

<p>1 (2.00 pm) 2 Opening statement by LLOYD WILLIAMS QC 3 SIR BRIAN LANGSTAFF: Lloyd Williams QC, instructed by the 4 clients of Watkins & Gunn. 5 MR WILLIAMS: Sir, I have been told that I can tell you what 6 those I represent want from this Inquiry. That can be 7 dealt with under three headings. 8 Firstly, they want their stories heard, not just in 9 here, not just in London, but throughout the United 10 Kingdom. They want their stories publicised. Secondly, 11 they want the truth. Thirdly, they want justice. 12 Ladies and gentlemen, my name is Lloyd Williams and, 13 together with Mr Christian Howells of counsel, and 14 instructed by Watkins & Gunn, we have the great honour 15 to represent 109 core participants, of whom 106 are 16 infected and affected individuals from the United 17 Kingdom. 18 They are largely concentrated in Wales and Northern 19 Ireland. 20 Sir, I am pleased to say that many of them were able 21 to make the real effort to be here yesterday and some 22 are still here today. 23 One other individual I represent is Julie Morgan, 24 a representative of the Welsh Assembly, founding member 25 of the cross party group of the Welsh Assembly on</p> <p style="text-align: center;">Page 1</p>	<p>1 position, being permitted to make an opening statement 2 when we have not seen a single witness statement and 3 have not yet had sight of a single disclosed document. 4 One happy result of that -- if that's the right way 5 to put it -- is that what I am about to say represents 6 the unvarnished views, opinions and wishes of those we 7 represent. What I am about to tell you hasn't been 8 massaged by the lawyers, hasn't been edited, it is 9 exactly what we have been told. 10 In the time that's been available we have consulted 11 with such of our clients who we could see, but in 12 particular Haemophilia Wales and 13 Haemophilia Northern Ireland. At the outset I should 14 make it clear that, unless the situation otherwise 15 requires it, I am not going to call those we represent 16 "the infected and affected". Those we spoke to, at 17 least for the purpose of the opening statement, find 18 those rather bland terms, nor did they wish to be called 19 "the survivors" because many haven't survived. 20 For the purpose of this opening statement, those we 21 spoke to said they wished to be called "the victims", 22 the victims of an appalling and wholly avoidable medical 23 disaster, but victims who have fought back. This 24 Inquiry is testament to the way they fought back. 25 Further, Sir, unless the context otherwise requires</p> <p style="text-align: center;">Page 3</p>
<p>1 haemophilia and contaminated blood, and has always been 2 a stalwart supporter of those who have fought for 3 justice. 4 We also represent Haemophilia Wales and Haemophilia 5 Northern Ireland, charitable organisations that 6 represent the interests of their members; those who have 7 received infected blood products and their families. 8 Their membership also includes those who received 9 infected blood transfusions and their families. They 10 are an umbrella organisations and through them we 11 represent the interests of many others. 12 Haemophilia Wales is a longstanding charity and has 13 campaigned for many years on behalf of those 14 contaminated with this blood, seeking to right the 15 wrongs that were done and that are still being done. 16 Lynne Kelly, a driving force behind 17 Haemophilia Wales, has already been given a name check 18 this morning, but I'll give her another one now. Very 19 much the driving force behind Haemophilia Wales -- 20 although, of course, I acknowledge there are many 21 others -- and someone who has sought to unite the people 22 in Wales affected by contaminated blood. 23 Sir, we know that you are anxious to get into the 24 substance of the Inquiry as soon as possible, but as 25 a result of that we find ourselves in a somewhat curious</p> <p style="text-align: center;">Page 2</p>	<p>1 it, I am simply going to refer to blood and blood 2 products as "blood products". I intend to review, in 3 turn, the three points that those I represent wish you 4 to consider. 5 Firstly, they want to tell their stories. A word of 6 warning: one should not underestimate the sheer anger 7 felt by the victims. Their feelings are as raw today as 8 they have ever been. We were presented with a stark 9 example of that during our consultation with a group of 10 victims. A woman whose two brothers had died having 11 been infected with Hepatitis C, she cut through the 12 discussions we were having and said, in a firm and clear 13 way, that she regarded her two brothers as having been 14 murdered. Not everyone of those we represent would use 15 that particular word, but all would share the anger she 16 felt at the wholly unnecessary and avoidable deaths. 17 The victims want their stories heard and, as we know 18 from yesterday, Sir, what appalling stories they have to 19 tell. They are the wholly innocent victims of 20 catastrophic failures on the part of American drug 21 companies, government -- using that in the widest sense 22 possible -- the providers of health services and the 23 medical profession, failures which have condemned 24 thousands to an early death and many more thousands to 25 lives dominated by ill-health, fear, anger and</p> <p style="text-align: center;">Page 4</p>

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<p>1 impoverishment.</p> <p>2 The victims we spoke to, Sir, feel it is important</p> <p>3 at this stage that the Inquiry is given a flavour of how</p> <p>4 their lives have been destroyed. There are a number of</p> <p>5 themes that need to be considered. They are as follows:</p> <p>6 (1) the initial shock of being told of the infection;</p> <p>7 (2) the ill-health associated with infection, which in</p> <p>8 many cases compounded the ill health associated with</p> <p>9 pre-existing haemophilia;</p> <p>10 (3) The treatment they have received for Hepatitis C,</p> <p>11 Interferon itself could have severe side effects,</p> <p>12 sometimes resulting or bringing about death. The side</p> <p>13 effects were well known to the medical profession, but</p> <p>14 of which their patients were not informed;</p> <p>15 (4) The various forms of treatment they have received to</p> <p>16 deal with the damage caused by Hepatitis C and HIV,</p> <p>17 including, but not limited to liver transplants that</p> <p>18 many underwent to remove cancerous livers directly</p> <p>19 caused by Hepatitis C;</p> <p>20 (5) The combined effect of Hepatitis C and HIV for those</p> <p>21 unfortunate enough to have been infected with both</p> <p>22 viruses;</p> <p>23 (6) This is a recurring point, Sir, of great importance:</p> <p>24 the stigma attached to the two conditions and ostracism</p> <p>25 which resulted, for the victims and their families, from</p> <p style="text-align: center;">Page 5</p>	<p>1 the appalling features of this disaster, and one which</p> <p>2 could be laid firmly at the door of the Department of</p> <p>3 Health, is that there may be thousands or perhaps, as we</p> <p>4 heard this morning, tens or hundreds of thousands of</p> <p>5 people who are wholly unaware that they were exposed to</p> <p>6 contaminated blood products and that they may have</p> <p>7 contracted Hepatitis C.</p> <p>8 Sir, as a barrister, my work involves representing</p> <p>9 badly injured people, with severe brain injury and</p> <p>10 spinal injury, and to do that work you have to, to an</p> <p>11 extent, harden yourself to hear the stories from your</p> <p>12 clients. But as Mr Howells and I have travelled from</p> <p>13 Cardiff to Belfast on a number of occasions, it was</p> <p>14 impossible not to be moved by the appalling stories we</p> <p>15 were told; each one different, each one a different</p> <p>16 variety of suffering.</p> <p>17 Those we represent wish me to put before you some</p> <p>18 examples which cover the issues which we have just</p> <p>19 identified. The first one was a 17 year old lad</p> <p>20 suffering from haemophilia whilst attending hospital for</p> <p>21 one of his regular appointments. He was told by the</p> <p>22 treating doctor that he had HIV. He was told not to</p> <p>23 tell anyone about it, not even his mother. He was told</p> <p>24 he had about 18 months to live. He regarded it as many</p> <p>25 did at the time, Sir, as a death sentence. He was not</p> <p style="text-align: center;">Page 7</p>
<p>1 the community in which they lived;</p> <p>2 (7) The shock of finding out that their infection could</p> <p>3 have been avoided;</p> <p>4 (8) The anger, resentment and bitterness they feel</p> <p>5 towards those whom they trusted and were entitled to</p> <p>6 trust, particularly the Department of Health;</p> <p>7 (9) The financial devastation that followed infection;</p> <p>8 (10) The ruined family and private lives of the victims;</p> <p>9 (11) The guilt that the victims feel about potential</p> <p>10 infection of their loved ones and the burden they feel</p> <p>11 they have become to their families;</p> <p>12 Finally, the guilt that the wholly innocent parents</p> <p>13 feel for not questioning the treatment which was</p> <p>14 provided to their children and, in some cases, being the</p> <p>15 ones who administered the contaminated blood products at</p> <p>16 home.</p> <p>17 This of course, Sir, is not an Inquiry simply</p> <p>18 looking back into the past. It is an Inquiry into the</p> <p>19 here and now, and it is an Inquiry into the future. The</p> <p>20 victims want to make it clear in their evidence that</p> <p>21 they have suffered not just for the last 40 years, but</p> <p>22 they suffer now, and they and their families will</p> <p>23 continue to suffer.</p> <p>24 Indeed, some infected by contaminated blood don't</p> <p>25 even know the suffering they are about to face. One of</p> <p style="text-align: center;">Page 6</p>	<p>1 provided with any support or counselling whatsoever, and</p> <p>2 he was unable to confide in anyone because of the stigma</p> <p>3 attached to HIV. Thereafter, he took to excessive</p> <p>4 consumption of sleeping tablets, together with morphine</p> <p>5 and other drugs, to try and numb his feelings. He was</p> <p>6 regularly admitted to hospital for treatment for</p> <p>7 haemophilia, where he saw other haemophiliacs, his</p> <p>8 friends, dying from AIDS. He had a nervous breakdown.</p> <p>9 He was admitted to a psychiatric hospital. Later, he</p> <p>10 was informed that he had been infected with Hepatitis C</p> <p>11 and was then treated for cirrhosis of the liver.</p> <p>12 Notwithstanding his original prognosis, he is still</p> <p>13 alive today. As a result of becoming infected with HIV</p> <p>14 and Hepatitis C, the way in which he was informed that</p> <p>15 he had contracted those diseases, the complete lack of</p> <p>16 counselling provided and the treatment he's undergone</p> <p>17 for those diseases, he regards his life as ruined. He</p> <p>18 and his wife live a hand to mouth existence, having to</p> <p>19 apply for financial support, or as he puts it, Sir,</p> <p>20 carrying around a begging bowl. Such applications for</p> <p>21 financial support usually being turned down.</p> <p>22 Another case: a lady was given a blood transfusion</p> <p>23 many years ago, during the birth of one of her children.</p> <p>24 That transfusion was infected with Hepatitis C. She</p> <p>25 developed cirrhosis of the liver and, later, liver</p> <p style="text-align: center;">Page 8</p>

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<p>1 cancer and has undergone two liver transplants. She has 2 suffered from other very serious ailments as a result of 3 the transfusion, which meant that a considerable 4 proportion of her life has been spent inside the 5 hospital doors. So has her husband, who spent long 6 periods of his life inside various hospitals in 7 Northern Ireland and London, whilst at the same time 8 trying to raise and support their children.</p> <p>9 Consequently, the land maps of every day family life 10 that people take for granted, such as weddings, 11 birthdays, family parties, have been extremely difficult 12 for this couple to attend. She has been unable to go on 13 holiday because of the cost of insurance and the fact 14 that she has to be within three hours of a transplant 15 hospital. She has the good fortune of having been in 16 a long and happy marriage with her husband, but when 17 diagnosed with Hepatitis C, she underwent the 18 humiliating and commonly asked questions, or 19 allegations, about how many sexual partners she had had 20 and whether she was a user of illicit drugs.</p> <p>21 Sir, notwithstanding the severity of the illnesses 22 she has suffered, in some ways the most significant 23 effect upon her is the overwhelming sense of guilt she 24 suffers. Guilt because she fears she has passed on the 25 infection to her children and grandchildren, who are</p> <p style="text-align: center;">Page 9</p>	<p>1 for an unrelated health care matter that he was asked to 2 meet a consultant, and he was informed for the very 3 first time that a pint of blood that he had been given 4 when he was 14 years old, during that eye surgery, was 5 infected with Hepatitis C. They were even able to give 6 him the batch number which contaminated him.</p> <p>7 The doctor who told him had picked it up from a note 8 contained in his medical records. He hadn't been told 9 of it before that time. He continues to try to work, 10 although suffering from serious medical complaints. He 11 complains of unjustifiable difficulty in obtaining 12 medical and dental treatment.</p> <p>13 Sir, if I may use the blunt, colourful language he 14 used when we spoke to him, he felt that he had been 15 treated as a mushroom. He had been kept in the dark and 16 fed bullshit by doctors, by the Department of Health and 17 by the government. Although many people wouldn't use 18 those words, many people feel the same.</p> <p>19 That man's brother was also a mild haemophiliac. 20 When a teenager, he suffered a minor bleed playing 21 a game of football. He was treated with blood products 22 resulting in Hepatitis C. Neither he nor his parents 23 were advised of alternative treatment that would have 24 avoided or materially reduced the risk of contamination. 25 He went on to develop cirrhosis of the liver. He is not</p> <p style="text-align: center;">Page 11</p>
<p>1 currently being tested for Hepatitis C, guilt because 2 she feels she has become a burden to her husband and the 3 family.</p> <p>4 When her condition became more widely known, her 5 daughter was bullied and ostracised at school. For most 6 of this woman's life she felt that she was the only one 7 who had suffered in this way. It was only when this 8 Inquiry was announced and the publicity emerged that she 9 realised she wasn't a lone sufferer.</p> <p>10 Another case: a middle aged man, who suffered from 11 mild haemophilia, underwent an elective, minor procedure 12 to his eye as a 14 year old boy, during this procedure 13 he was given a blood transfusion. Neither he nor his 14 parents were given any warning about the risk of 15 contaminated blood products and so were deprived of the 16 opportunity to make an informed decision as to whether 17 to proceed with a surgery with full knowledge of the 18 risks. He developed Hepatitis C. Symptoms only became 19 apparent in his 30s, by which time he was married, with 20 children, holding down a responsible job. As a result 21 of him becoming unwell, his wife divorced him, he became 22 a estranged from his sons and he hasn't seen them for 23 over 20 years. He developed liver cancer and he's had 24 two liver transplants.</p> <p>25 It was only when he was in hospital, in Newcastle,</p> <p style="text-align: center;">Page 10</p>	<p>1 critical of the subsequent medical treatment he 2 received, but he does complain bitterly that for some 3 time he was not allowed to examine his own medical 4 notes. He recalls being invited to a meeting at the 5 haemophilia centre with other haemophiliacs when they 6 were asked whether they wanted to know if they had been 7 infected with Hepatitis C and HIV. There had been no 8 forewarning, it was a group meeting. It was apparent 9 that his blood had been tested without his consent and 10 that the health authorities and/or the doctors had known 11 for some time of his contamination. He also received an 12 unsolicited letter in the post asking the same question: 13 did he want to know whether he had Hepatitis C or HIV.</p> <p>14 Sir, recently a case came to light of a lady who 15 contracted Hepatitis C as a result of receiving a blood 16 transfusion in 1979 for rheumatoid arthritis. In 2010, 17 she was hospitalised with septic arthritis in her hip. 18 It was only at that point that a doctor suspected that 19 her symptoms were caused by Hepatitis C and had her 20 tested with her consent. Thus it was discovered that 21 she had lived with undiagnosed Hepatitis C for 31 years. 22 She now has early onset dementia, and it has been 23 suggested there is a link between the undiagnosed 24 Hepatitis C and the dementia.</p> <p>25 A stark example of how decisions made by doctors</p> <p style="text-align: center;">Page 12</p>

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<p>1 could so severely affect a person's life is that of two 2 brothers, both mild haemophiliacs. One brother attended 3 hospital with a bleeding nose, which was treated with 4 Factor 8. However, that treatment didn't stop the bleed 5 and so his nose was cauterised.</p> <p>6 As a result of the treatment with Factor 8, he 7 contracted Hepatitis C. The lack of appropriate advice 8 and warning deprived him of the opportunity of avoiding 9 treatment with Factor 8. His brother, simply by good 10 fortune, did not require treatment during that period 11 and so does not have Hepatitis C.</p> <p>12 The selection of Factor 8 above all other possible 13 treatments meant that the doctors were playing Russian 14 roulette with his life, as happened in so many other 15 cases. It was a game of which the victims, their 16 patients, were wholly unaware was being played.</p> <p>17 Sir, one of the victims wrote to us in the following 18 terms, and it bears repeating in full. It is from 19 a couple, and they say this:</p> <p>20 "From our experience, the UK Government has been 21 evasive, dishonest and cynical. The Department of 22 Health has been hostile in its responses to campaigners 23 and MPs who have debated in Parliament. They have 24 refused to both fully accept responsibility and to offer 25 realistic compensation. They have engaged in political</p> <p style="text-align: center;">Page 13</p>	<p>1 become ill. We have often given up our jobs and careers 2 to nurse and care for them, enduring hardships in 3 consequence. We have had to endure the stigma of these 4 illnesses with them. We have suffered harassment and 5 prejudice, and often been too frightened to tell our 6 families about the truth of loved ones, perhaps lying or 7 keeping secrets.</p> <p>8 "We have had to tell our children, if we have been 9 able to have them, that their father was ill and dying, 10 while others have been denied the chance of ever having 11 children. We have watched our loved ones slip away, 12 hold their hands as they do, and see them die horrific 13 deaths, bury them and, afterwards, try to rebuild our 14 lives with the constant background with this travesty in 15 our minds and with little support.</p> <p>16 "Many have been unable to work again. They have 17 been traumatised, had breakdowns, been left to become 18 single parents and bring up children who have been left 19 without fathers. A few widows have become homeless or 20 have committed suicide."</p> <p>21 Sir, the developing nature of the evidence was 22 brought home to me this morning when Lynne Kelly of 23 Haemophilia Wales introduced me to a lady who told me an 24 appalling story, which only goes to confirm the general 25 attitude of the Department of Health.</p> <p style="text-align: center;">Page 15</p>
<p>1 trickery and treated victims with contempt. The 2 Department of Health clearly has a lot to hide and has 3 been aggressive in its defence of its own interests. 4 The financial assistance given has been piecemeal and 5 grudging. The use of contaminated blood and its 6 consequences is a scandal, but the attitude of the 7 Department of Health to victims is an even bigger 8 scandal, provoking great anger, distress and suffering, 9 adding insult to injury."</p> <p>10 Sir, the bereaved partners who have cared for the 11 victims, often giving up their own careers to do so, 12 then having to rebuild their lives, often whilst caring 13 for their children, has placed enormous burdens, 14 usually, although not wholly, on women. The tap was 15 turned off on the trickle of financial support three 16 years after the death of their loved one. Thereafter, 17 they were left to fend for themselves.</p> <p>18 One widow, who we represent, wrote to us in the 19 following terms:</p> <p>20 "All widows have been given a life sentence. Some 21 a double life sentence, if infected as well, for a crime 22 we did not commit, and we suffer daily from something we 23 did not do. We have been there when our husbands have 24 discovered that they have become HIV positive and/or 25 Hepatitis C positive. We have watched our loved ones</p> <p style="text-align: center;">Page 14</p>	<p>1 This was a lady who was a blood donor. She had been 2 donating blood -- and I have her blood donation card 3 here -- donating blood from 1987 to 1992. When she went 4 for the last donation of blood on 26 February 1992, she 5 was told that she couldn't donate any more blood as she 6 had Hepatitis C. It was subsequently discovered she had 7 had Hepatitis C for many, many years, having been 8 infected in 1975. All those years, from 1987 to 1992, 9 she had donated contaminated blood. There had been no 10 attempt to track her down, no attempt to prevent her 11 from doing what she thought was best, which was trying 12 to help her fellow citizens. She had been infected by 13 blood after receiving a transfusion.</p> <p>14 She told me this morning she felt like a murderer 15 for what she'd done, in simply donating blood.</p> <p>16 Sir, a recurring theme is the great difficulty 17 people have faced in obtaining their medical records, 18 and that when the records have been obtained they have 19 crucial periods missing from them or, on the other hand, 20 they reveal that the medical practitioners knew of the 21 infection long before they informed the victim.</p> <p>22 One striking example of this involves a teenager, 23 a haemophiliac, who went to Australia for a year and was 24 given a supply of Factor 8 by his treating consultant, 25 in Cardiff. Whilst in Australia he suffered a bleed in</p> <p style="text-align: center;">Page 16</p>

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<p>1 his kidney and he used the Factor 8 to treat it. 2 Subsequently, his mother, whilst speaking on the 3 telephone to his consultant in Cardiff, was told that he 4 had HIV and was told not to tell her son. Thereafter, 5 she discovered that her son had been told by the 6 consultant that he had HIV, but that he should not tell 7 anyone and he should keep it strictly confidential for 8 his own good. 9 Years later, as a result of a civil claim, his 10 mother had disclosed to her a letter written by that 11 consultant to a doctor in Australia and, once again, it 12 bears reading: 13 "I am really writing to you about young [and I'll 14 call him John for the purpose of this] ... the boy with 15 haemophilia who was visiting the Brisbane area and who 16 you very kindly treated when he was in need. You may 17 have heard in the press that there is a minor flurry of 18 anxiety in the UK concerning AIDS. You may also have 19 heard that I have a patient, who although by no means 20 resembles the severe American cases may have the mildest 21 form, at least he has some of the features. Checking 22 back over our records we find that John had received 23 Factor 8 concentrate for one of the batches used for our 24 suspect patient in 1980. I wonder if it would be 25 possible to keep a gentle eye on John without letting</p> <p style="text-align: center;">Page 17</p>	<p>1 statements from recollection of events, which may have 2 taken place over four decades ago without the assistance 3 of the contemporaneous records. This Inquiry should not 4 become a memory game. Moreover, individuals cannot 5 recollect that which they were not told. 6 The very important point is this: in order to enable 7 the victims to truly give the evidence of what happened 8 to them, their medical records must be reviewed prior to 9 their witness statements being prepared. This must 10 surely be uncontroversial. Yet it has been suggested by 11 the Inquiry team that our clients should obtain their 12 medical records by themselves and then, if they wish, 13 they can review those records. This obviously is an 14 unsatisfactory state of affairs. 15 Sir, you will know only too well how difficult it 16 can be to obtain all relevant medical records and then 17 to decipher them. It is often the experience of those 18 representing injured persons that their medical notes 19 can be found in many locations, sometimes where they 20 might not be expected to be found. To put it shortly, 21 they need to be traced. 22 We call on the Inquiry to promise the victims that 23 they will be assisted, if necessary, by their legal 24 representatives in obtaining their medical records and 25 in understanding the medical records.</p> <p style="text-align: center;">Page 19</p>
<p>1 him know the reason why. I do not anticipate any 2 trouble, but I think it would be remiss of me not to 3 follow things up." 4 What appalling, breathtaking arrogance on the part 5 of that consultant. The suspect patient was treated 6 with the blood in 1980. "John", as I have called him, 7 was treated in 1983 with blood from the same batch. He 8 wasn't told that he had HIV until 1985. That letter, 9 confirming the earlier knowledge of the doctor, was only 10 found by the hard work of those seeking to assist John 11 in later life. John's now dead. 12 Clearly, Sir, one of the most important functions of 13 this Inquiry is to facilitate every person who wants to 14 give their account of what happened, to give their 15 evidence and to listen to them. It goes without saying 16 that the evidence should be as accurate as possible. We 17 know the Inquiry appreciates this and is in the process 18 of ensuring that, between now and the end 19 of January 2019, everyone who wants to can give 20 a witness statement. 21 As part of the process of making a witness 22 statement, it is vital that witnesses are able to refer 23 to the contemporaneous medical records. It would be 24 wholly unacceptable for people who may be vulnerable or 25 be traumatised to be left to make their witness</p> <p style="text-align: center;">Page 18</p>	<p>1 One of the trustees of Haemophilia Wales, and one 2 used to dealing with medical practitioners, explained to 3 us last week the difficulty he had had in obtaining his 4 own medical notes. When he initially requested them, he 5 was supplied only with a disc containing his haemophilia 6 centre notes from 1983 onwards. His insistence that 7 this cannot be the sum total of his notes in existence 8 led him to a meeting with the legal team at Cardiff & 9 Vale University Health Board. It took place some two 10 weeks ago. 11 Thereafter, an investigation was carried out and 12 four files of his notes were found in archives, together 13 with the notes of many others. This is but one example 14 of the difficulties involved and why the victims are 15 entitled to representation, to ensure that they obtain 16 their notes in full, insofar as they still exist. 17 A further complicating factor is the short timescale 18 for the production of witness statements once a witness 19 cost order has been made, just 21 days. This makes it 20 near impossible to obtain and review medical records 21 before the production of a witness statement. We invite 22 the Inquiry to extend that time period so as to allow 23 that process properly to happen. 24 If this is not done, then the Inquiry will fail in 25 this singularly most important function and the victims</p> <p style="text-align: center;">Page 20</p>

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<p>1 will not be able to tell the Inquiry their story, as in 2 a large number of cases they will either have forgotten 3 various events or dates, or they won't know them all in 4 detail.</p> <p>5 More generally, patterns of behaviour and misconduct 6 disclosed in the medical records will only be identified 7 if each and every set of medical records is reviewed. 8 It is already overwhelmingly apparent to us that the 9 medical records have a story to tell.</p> <p>10 Sir, this Inquiry must allow that story to be told. 11 Finally, on this matter, it is important that the 12 victims are able to give their evidence in their own 13 words. If this includes strong, frank language, then so 14 be it.</p> <p>15 This must also include their ability to give 16 evidence in their mother tongue, and we know of at least 17 one core participant who wishes to give his evidence in 18 Welsh and we would respectfully say that he should be 19 permitted to do so.</p> <p>20 I turn to the second matter, the truth. What do the 21 victims want? 22 They want the truth. 23 When do they want it? 24 30 years ago. 25 The victims are angry that the government has not</p> <p style="text-align: center;">Page 21</p>	<p>1 These questions are matters which were raised with 2 us directly. We have simply put them into order in 3 trying to set out, in a comprehensive way, the matters 4 they want to be pursued. No doubt, during the course of 5 the Inquiry, other matters will emerge and, no doubt, 6 there will be other issues which seem important to them, 7 but at the moment it is this: American drug companies. 8 They want to know why the American drug companies chose 9 to buy blood from prisoners, drug addicts, those on the 10 edge of society, when they knew that there was 11 a substantially increased risk that the blood would be 12 contaminated with Hepatitis C and then, eventually, HIV. 13 They want to know when and in what circumstances the 14 drug companies came by this knowledge. They want to 15 know what information regarding this risk the drug 16 companies gave to the purchase of this blood, in 17 particular the UK Government and health services. If 18 they did give information or warnings to the UK 19 Government or health services about the increased risk 20 of contamination, then what did they tell them, and 21 when, to whom, in what form was that information 22 transmitted? 23 They want to know what measures, if any, were taken 24 to avoid or materially reduce the risk of blood products 25 being so contaminated.</p> <p style="text-align: center;">Page 23</p>
<p>1 faced up to what happened before now and accepted 2 responsibility. During those years, they have had to 3 fight tooth and nail for everything, including treatment 4 and financial support. Not only that, but because of 5 the stigma attached to Hepatitis C and HIV many of the 6 victims kept their ill-health secret, so that 7 consequently they did not know the extent of the 8 disaster and many thought that they were the only ones 9 who were suffering.</p> <p>10 Many of the victims have campaigned for 30 years or 11 more for a public Inquiry, and this Inquiry is the first 12 and the last opportunity for the victims to know the 13 truth about why, for what reasons and in what 14 circumstances they were exposed to contaminated blood 15 products.</p> <p>16 It is of the utmost importance and they know it is 17 your intention to get to the truth of what happened. 18 What do they want the truth about? 19 In one sense, Sir, the answer to the question is 20 quite simple and straightforward. They want to know the 21 truth about everything concerning the desperate position 22 in which they have been placed by the actions of others. 23 They appreciate, however, that you seek something 24 a little more specific today and so, in essence, they 25 seek the truth about the following matters:</p> <p style="text-align: center;">Page 22</p>	<p>1 They want to know if the drug companies adopted 2 a different policy regarding warnings of the increased 3 risk and measures to avoid or reduce that risk in 4 regards to their dealings with the American Government 5 and health services. In other words, they want to know 6 the extent to which the drug companies discriminated 7 against non-Americans.</p> <p>8 They want to know about the methods of production of 9 blood products adopted by these companies in regard to 10 the blood they had harvested.</p> <p>11 Self-sufficiency. They want to know why it is that, 12 by the early 1970s, the UK was not self-sufficient in 13 the production of safe blood products. They want to 14 know why it is that, when the UK Government and health 15 services started to become aware that the blood products 16 they were buying from the drug companies might be 17 contaminated with Hepatitis C or HIV, measures were not 18 immediately put in place to enable the UK to be wholly 19 self-sufficient in the production of safe blood 20 products.</p> <p>21 They want to know what information was provided to 22 Lord Owen, Dr David Owen, Minister for Health, as he 23 then was in 1974, that made him so concerned regarding 24 the contamination of blood products purchased from 25 America that he directed that measures should be put in</p> <p style="text-align: center;">Page 24</p>

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<p>1 place to become self-sufficient within five years.</p> <p>2 They want to know why it took so many more years to</p> <p>3 reach self-sufficiency in England and Wales. By way of</p> <p>4 comparison, we see that Ireland, who also set a period</p> <p>5 of five years to achieve self-sufficiency, were able to</p> <p>6 do so within that timescale.</p> <p>7 They want to know how Scotland became</p> <p>8 self-sufficient in the production of blood products at</p> <p>9 an earlier date than the rest of the UK. They want to</p> <p>10 know why, despite the fact that Scotland had available</p> <p>11 surplus capacity to produce blood products, the UK</p> <p>12 Government or the health services failed to make use of</p> <p>13 it. They want to know what happened to the money that</p> <p>14 Lord Owen set aside to achieve self-sufficiency in five</p> <p>15 years.</p> <p>16 The role of the UK Government. They want to know</p> <p>17 what inquiries or investigations were carried out by the</p> <p>18 UK Government regarding any potential risks posed by the</p> <p>19 purchase of blood products from drug companies. They</p> <p>20 want to know if any inquiries or investigations were</p> <p>21 carried out, and what prompted those inquiries. They</p> <p>22 want to know what information was obtained and was it</p> <p>23 acted upon. They want to know what inquiries or</p> <p>24 investigations should have been made by the UK</p> <p>25 Government to ensure that any blood products purchased</p> <p style="text-align: center;">Page 25</p>	<p>1 drug companies and/or the UK Government, which resulted</p> <p>2 in known risks being disregarded or minimised.</p> <p>3 They want to know what investigations and measures,</p> <p>4 if any, were taken to ensure that blood products</p> <p>5 produced in the UK were safe. They want to know why it</p> <p>6 is that so many relevant documents, for example those</p> <p>7 put before Lord Owen, have been destroyed or lost. They</p> <p>8 want to know: why did it take the government so long to</p> <p>9 establish a public Inquiry?</p> <p>10 They want to know: why did the government fail to</p> <p>11 provide witnesses to the non-statutory Archer Inquiry?</p> <p>12 They want to know to what extent there has been</p> <p>13 a conspiracy of silence on the part of government. They</p> <p>14 want to know why has the government failed to put in</p> <p>15 place a comprehensive, UK-wide system of compensation</p> <p>16 for the victims.</p> <p>17 They want to know why there is such variation in</p> <p>18 the systems set up for the administration of financial</p> <p>19 assistance. They want to know why there are different</p> <p>20 categories of victims that receive different levels of</p> <p>21 financial assistance, in particular, why has there been</p> <p>22 rank discrimination against widows.</p> <p>23 They want to know what role, if any, did the drug</p> <p>24 licensing authorities play in authorising or permitting</p> <p>25 the supply of potentially contaminated blood products.</p> <p style="text-align: center;">Page 27</p>
<p>1 from America were safe.</p> <p>2 They want to know when, by whom, and in what</p> <p>3 circumstances the UK Government first became aware of</p> <p>4 the use of blood products from drug companies posed</p> <p>5 a risk to UK citizens. They want to know to what extent</p> <p>6 there was cooperation between various departments of</p> <p>7 government and, in particular, why was contradictory</p> <p>8 advice given by various departments?</p> <p>9 They want to know what actions, if any, were taken</p> <p>10 by the UK Government when they became aware of the risks</p> <p>11 posed by blood products purchased from American drug</p> <p>12 companies. They want to know what guidance, if any, was</p> <p>13 given to the health service regarding the potential</p> <p>14 risks posed by blood products purchased from drug</p> <p>15 companies. If none was given, why not?</p> <p>16 They want to know: why did the government not impose</p> <p>17 an immediate prohibition on the purchase of blood</p> <p>18 products from drug companies when the risks became</p> <p>19 known?</p> <p>20 They want to know why there wasn't a uniformed</p> <p>21 system of procurement, either by the establishment of</p> <p>22 a central agency or by the issuance of guidance.</p> <p>23 They want to know to what extent was the purchase of</p> <p>24 blood products from drug companies influenced by</p> <p>25 conflicts of interest or commercial interest held by the</p> <p style="text-align: center;">Page 26</p>	<p>1 Devolved government. As the majority of our clients</p> <p>2 have a particular interest in Wales and</p> <p>3 Northern Ireland, it is necessary to consider whether</p> <p>4 the differences in the form of government will lead to</p> <p>5 different considerations which will require careful</p> <p>6 examination, in particular the chain of responsibility</p> <p>7 for decisions and/or actions and what were the practical</p> <p>8 differences in outcome.</p> <p>9 Looking for one moment at Northern Ireland, from</p> <p>10 1970 to 1972 it had its own Parliament at Stormont with</p> <p>11 full responsibility for health.</p> <p>12 From 1972 to 1999, there was a period of direct rule</p> <p>13 when it appears that the Secretaries of State for</p> <p>14 Northern Ireland may have had some responsibility for</p> <p>15 health.</p> <p>16 From 1999 to 2002, there was a devolved assembly</p> <p>17 which had responsibility for health. That was followed</p> <p>18 by a period of direct rule when some responsibility for</p> <p>19 health appears to have reverted back to the Secretary of</p> <p>20 State.</p> <p>21 From 2007, responsibility returned to the Assembly.</p> <p>22 More recently, the last 18 months, the constitutional</p> <p>23 position is unclear.</p> <p>24 The Northern Ireland victims want to know the extent</p> <p>25 to which the different structure of government and the</p> <p style="text-align: center;">Page 28</p>

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<p>1 different decision-making processes that existed may 2 have led to an enhanced risk of contracting Hepatitis C, 3 HIV and, further, the impact this may have had on the 4 provision of care and treatment in that country.</p> <p>5 In respect of Wales, from 1970 to 1999 the Secretary 6 of State for Wales had some responsibility, the extent 7 of which is unclear, for the health service.</p> <p>8 Sir, the letter that has been posted on the 9 Inquiry's website from the chief executive of the 10 Cardiff & Vale University Health Board, dated 11 12 September 2018, makes it clear that, until 1988, 12 regional blood transfusion centres were managed by 13 regional health authorities, with the Welsh office -- in 14 other words, the Secretary of State -- managing the 15 Cardiff transfusion centre.</p> <p>16 Further, the Haemophilia Centre, based at the 17 University Hospital of Wales, acted autonomously when it 18 came to the selection of blood products.</p> <p>19 It would seem that might have been managed by the 20 Secretary of State for Wales from 1999 onwards, as 21 a result of devolution, as the Welsh Assembly Government 22 has undertaken responsibility for health and the 23 provision of health services.</p> <p>24 The Welsh victims have similar concerns to those in 25 Northern Ireland regarding the extent to which there</p> <p style="text-align: center;">Page 29</p>	<p>1 place by those bodies to ensure that only safe blood 2 products were obtained. They want to know what 3 measures, if any, were put in place by those bodies to 4 ensure that blood products produced in the UK were safe. 5 They want to know why they failed to ensure that users 6 or potential users of blood products were given 7 appropriate warnings or advice regarding the potential 8 risks they faced regarding the use of contaminated blood 9 products.</p> <p>10 They want to know why they failed to establish 11 a system and/or policy for advising haemophiliacs of 12 alternative methods of treatment which could have 13 avoided, or materially reduced, the risk from blood 14 products. Why was it left to individual medical 15 practitioners to decide what advice would be given?</p> <p>16 They want to know why they failed to establish 17 a system for informing victims that they had contracted 18 Hepatitis C or HIV. They want to know why they failed 19 to establish a system for the provision of counselling 20 and other support services to victims after they were 21 diagnosed with Hepatitis C or HIV. They want to know 22 why they failed to establish a system for the provision 23 of information regarding the risk of contamination of 24 their partners or other members of their family, and how 25 those risks could be minimised or otherwise managed.</p> <p style="text-align: center;">Page 31</p>
<p>1 were differences in the form of government and the 2 decision-making process, which may have exposed them to 3 an enhanced risk of harm and resulted in different 4 provision of health.</p> <p>5 It may well be that the Inquiry will benefit from 6 expert evidence on the respective constitutional 7 arrangements, both formal and informal, that were in 8 existence in Wales and Northern Ireland since 1970 up to 9 the present time.</p> <p>10 We also invite the Inquiry to consider whether the 11 various offices of the Secretary of State or devolved 12 governments possess or have access to copies of 13 documents that appear to have been lost or destroyed by 14 central government.</p> <p>15 Health services. They want to know what 16 responsibility do individual health services -- a term 17 used for the purpose of this opening statement in a very 18 general sense -- have for the selection and purchase of 19 blood products. They want to know to what extent did 20 those bodies have, or should have had, a uniform policy 21 for the purchase of blood products. They want to know 22 what measures, if any, were taken by those bodies to 23 collaborate with each other in the safe provision of 24 blood products.</p> <p>25 They want to know what measures, if any, were put in</p> <p style="text-align: center;">Page 30</p>	<p>1 They want to know why there has been a wide 2 disparity in the type and quality of treatment and 3 support services offered to those who have suffered 4 injury as a result of treatment with contaminated blood 5 products. They want to know to what extent was the 6 purchase of blood products from drug companies 7 influenced by conflicts of interest or commercial 8 interests held by the drug companies and/or the health 9 service, which resulted in known risks being disregarded 10 or minimised.</p> <p>11 They want to know what actions, if any, were taken 12 by these health authorities in response to the 13 developing knowledge of the risks associated with blood 14 products purchased from drug companies or those produced 15 in the UK. They want to know why they failed to ensure 16 that informed consent was obtained for treatment with 17 blood products in respect of which there was a risk of 18 contamination. They want to know why they failed to 19 ensure that informed consent was obtained for carrying 20 out tests on victims' blood. They want to know to what 21 extent they were the victims used as guinea pigs in 22 regard to the treatment they received or did not 23 receive. They want to know why they have been failed, 24 why they have failed to attempt to trace those 25 individuals who were at risk of being exposed to</p> <p style="text-align: center;">Page 32</p>

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<p>1 contaminated blood products, especially those who may 2 have received blood transfusions.</p> <p>3 They want to know why some patients' records have 4 been wrongfully interfered with, including the removal 5 of those parts of the records dealing with a likely date 6 and circumstances of contamination, the subsequent 7 testing of the patients' blood to confirm contamination, 8 and the period between when the medical practitioners 9 knew of the infection and when the victims were 10 informed.</p> <p>11 They want the know why so many death certificates 12 contained inaccurate or wholly misleading causes of 13 death when the true reason, death caused by Hepatitis C 14 or HIV, would have been clear and obvious from the known 15 history of the deceased. They want to know to what 16 extent there has been a conspiracy of silence on the 17 part of the health authorities.</p> <p>18 Medical professionals. They want to know has there, 19 since the 1970s, been a conspiracy of silence amongst 20 medical professionals regarding (1) what was known about 21 the supply of contaminated blood; (2) the fact that 22 patients had developed Hepatitis C or HIV; (3) the 23 testing of patients' blood without their consent; (4) 24 the failure to obtain informed consent for treatment, in 25 particular treatment which was avoidable.</p> <p style="text-align: center;">Page 33</p>	<p>1 It is little wonder that they grew resentful and 2 bitter towards government and health services, and 3 assumed that it was because they both had something to 4 hide, an inevitable reaction to the revelation that 5 Lord Owen's ministerial papers and other papers had been 6 destroyed without any apparent justification.</p> <p>7 Sir, I turn to the third matter, justice. Thousands 8 of people have died, thousands of people still suffer 9 from very severe ill health and, tragically, it is 10 likely that in the future thousands more will discover 11 that they have been infected with Hepatitis C and HIV.</p> <p>12 The victims regard this Inquiry as a search for 13 justice. There is a general view amongst the victims 14 that for over 40 years people in the know have kept 15 their mouths shut, their files closed and their 16 shredders busy. All they have received was a belated 17 apology from the Prime Minister in 2015. Where is the 18 justice in that?</p> <p>19 For the victims we represent, the following 20 represents the absolute minimum that is required for the 21 doing of justice: firstly, identify those responsible.</p> <p>22 They appreciate that the Inquiry cannot determine 23 questions of criminal or civil liability, but, 24 nonetheless, they want you to name the names. They want 25 to know the parties responsible for causing the</p> <p style="text-align: center;">Page 35</p>
<p>1 They want to know why were victims consistently not 2 told that they had contracted Hepatitis C and HIV, 3 notwithstanding it was recorded in their notes. They 4 want to know why doctors failed to inform patients, in 5 particular mild haemophiliacs, of the alternatives to 6 treatment with blood products potentially contaminated 7 with Hepatitis C or HIV. They want to know why they 8 failed to inform victims of the risk of infecting their 9 partners or other members of their family. They want to 10 know to what extent were the treating consultants, in 11 particular those in charge of Haemophilia Centres, 12 autonomous in the choice of blood products. To the 13 extent that they were, they want to know what was the 14 basis upon which decisions were made regarding the 15 purchase of blood products. They want to know why 16 doctors failed to warn patients of the known risks of 17 exposure to contaminated blood products.</p> <p>18 Sir, when considering the issues we have just 19 raised, or shall I say that have been raised with us 20 with those we represent, we invite the Inquiry to 21 consider the victims' view, that the suffering caused by 22 the initial industrial scale infection was exacerbated 23 by governments and health services inertia. Why did 24 they singly fail to treat those who were NHS and Blood 25 Transfusion Services with dignity?</p> <p style="text-align: center;">Page 34</p>	<p>1 devastating harm they've suffered. They want to know 2 the parties responsible for causing them or their loved 3 ones to be infected with Hepatitis C or HIV. They want 4 to know the parties responsible for causing the deaths 5 of their loved ones.</p> <p>6 The identification of those responsible is likely to 7 include individuals and more likely to include 8 institutions or the constituent parts.</p> <p>9 Decisions don't make themselves, actions don't 10 action themselves. Somebody makes the decisions or 11 omits to make a decision. Somebody acts or fails to 12 act.</p> <p>13 It is only by identifying those parties responsible, 14 for what has been described as the greatest untold 15 justice in the history of the NHS, that the victims will 16 find some closure.</p> <p>17 Sir, we don't want the parties to walk away from 18 this Inquiry shrugging their shoulders and say, "It 19 wasn't our fault, the chairman didn't blame us. He 20 didn't name us. He didn't hold us responsible". If 21 they were responsible, then they should be named.</p> <p>22 Provision of health services. As we have already 23 noted, and as we apprehend the evidence we reveal, the 24 provision of health services -- using that term in the 25 broadest sense -- is a history of failure to meet the</p> <p style="text-align: center;">Page 36</p>

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<p>1 real needs of the victims. The picture that will emerge 2 is a hotchpotch of ill thought out initiatives, where 3 health authorities are left to their own devices. 4 In some areas, more effective treatment is provided 5 than in other areas. It is an affront to human dignity 6 that the standard of treatment received or to be 7 received will depend on where in the UK an individual 8 happens to live. By way of example, we believe that the 9 most effective drug for treatment for Hepatitis C is 10 universally available in Wales and Northern Ireland, yet 11 it appears to be rationed in England. 12 The public is likely to be astonished at the 13 variations in health services provided to victims in the 14 UK. It brings this country into disrepute. 15 The victims hope, Sir, that this Inquiry will make 16 firm recommendations as to how, on a nationwide basis 17 and centrally funded, the highest quality of health 18 services can be provided to the victims. As you will no 19 doubt bear in mind, many of these victims already suffer 20 from the highly debilitating and sometimes fatal 21 condition of haemophilia, the contraction of Hepatitis C 22 and HIV has greatly compounded their existing condition. 23 More generally these viruses have given rise to 24 victims developing severe medical condition including 25 cirrhosis and cancer of the liver. These various</p> <p style="text-align: center;">Page 37</p>	<p>1 handed down from on high, but rather as the result of 2 proper consultation with the victims of this medical 3 disaster as to what treatment, care and support is to be 4 provided and how it is provided. They want a voice in 5 what happens to them and how they are treated. For over 6 four decades, up until the present time, they have had 7 to take what was handed out to them. Now they want to 8 take ownership so far as possible of their treatment, 9 care and support, permitting them to make informed 10 choices in relation to their treatment. What is sought 11 is a recommendation from you, Sir, that going ahead 12 there is a partnership between health services, doctors 13 and victims. 14 Compensation. In the past, the government has set 15 up and funded arm's length charitable organisations to 16 distribute some financial support to some victims. More 17 recently there have been changes to the way in which 18 these funds are administered, but any suggestion that 19 this represents proper compensation for the hurt they 20 have, they are and will continue to suffer is met with 21 anger and indignation. 22 The system which was developed presents a patchwork 23 of ill thought out, badly funded and discriminatory 24 support. 25 A recurrent complaint is that victims feel they have</p> <p style="text-align: center;">Page 39</p>
<p>1 medical conditions frequently result in death. All of 2 the victims require, and they would say they are 3 entitled to receive, comprehensive healthcare and 4 support services of the highest standard. 5 Consideration should be given to the scheme 6 established in Ireland after the Lindsay Inquiry, where 7 the victims are given a health card which enables 8 medical practitioners to identify the victims as 9 sufferers of the contaminated blood scandal, so that 10 there be no unnecessary discussion to take place. A 11 particularly important feature is that it also entitles 12 them to priority treatment. 13 In addition, Sir, we seek a recommendation that the 14 health services should be required to trace and properly 15 identify those individuals who may have been exposed to 16 treatment by contaminated blood products. These people 17 going about their everyday lives, blissfully unaware 18 that they may have developed Hepatitis C, should be 19 traced and, when found, be offered blood testing and 20 provided with such counselling, treatment and support as 21 may be necessary, as indeed was recommended as long ago 22 as the Penrose Inquiry. 23 Although we are aware that there have been some 24 isolated attempts to trace such people, there is no 25 nationwide procedure. These services should not be</p> <p style="text-align: center;">Page 38</p>	<p>1 to go cap in hand, like beggars, to seek the bare 2 minimum of support. It is discriminatory, derisive and 3 demeaning. The Byzantine complexity of the various 4 schemes results in clear categories of victims, in 5 particular widows and widows without children receiving 6 the absolute minimum of support. 7 In some cases, entitlement to financial support 8 depends on whether or not claims were registered by 9 certain dates. That is arbitrary and capricious. 10 One doesn't have to look far for a more generous and 11 humane system of support. As has been mentioned 12 already, in Ireland, in 2002, the government, following 13 a public Inquiry and whilst denying liability, accepted 14 responsibility and set up a far more sensible and 15 generous scheme for the support of their victims of the 16 contaminated blood scandal. 17 One can imagine the distress felt by victims by 18 people here today, in the UK, a far larger and wealthier 19 country, having to make do with crumbs that fall off the 20 table. They look to this Inquiry, Sir, to make 21 recommendations for a comprehensive system for the 22 payment of proper compensation to the victims without 23 discrimination; a system where there will be no need to 24 go cap in hand when an unexpected bill arrives on the 25 doormat, but rather compensation as of right.</p> <p style="text-align: center;">Page 40</p>

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<p>1 Compensation for those who have suffered, who 2 continue to suffer and those who will suffer in the 3 future, so as to allow them to regain independence and 4 some control over their lives.</p> <p>5 The first duty of a government must be to protect 6 its citizens. Where there has been such a lamentable 7 failure to do so, resulting in so many people, through 8 no fault of their own, suffering such loss, the least 9 that can be done is a proper system of compensation.</p> <p>10 Sir, in order to ensure this enquiry leaves 11 a meaningful legacy the victims we represent believe 12 that the issues we have raised on their behalf must be 13 effectively addressed. They must have their stories 14 heard, they must learn the truth, they must receive 15 justice. Sir.</p> <p>16 SIR BRIAN LANGSTAFF: Thank you very much, 17 Mr Lloyd Williams. We'll now take a 20 minute break. 18 Please be back promptly at 3.20. 19 (3.00 pm) 20 (A short break) 21 (3.20 pm) 22 SIR BRIAN LANGSTAFF: For the rest of the day we shall be 23 listening to two presentations, the first by 24 Sam Stein QC, the second by Karon Monaghan QC, on behalf 25 of two of the smaller groups of core participants:</p> <p style="text-align: center;">Page 41</p>	<p>1 and all too often also infected. The evidence 2 discovered by campaigners suggests that state bodies, 3 including the NHS, actively pursued human observation, 4 testing and experimentation that was unthinkable in the 5 wake of the development of The Nuremberg Code.</p> <p>6 With Alan Barker and instructed by Milners 7 solicitors, I appear on behalf of four core participants 8 and a witness from the infected and affected haemophilia 9 community. Through these opening submissions we shall 10 set out our representations as to how this Inquiry 11 should proceed in order to operate most effectively and 12 to support the participation of infected and affected 13 persons, and achieve the objectives of this Inquiry.</p> <p>14 Following this preliminary hearing, we will provide 15 a copy of our speaking notes. We will also draft and 16 file written submissions based and building on our oral 17 submissions, and provide comments on the proposed expert 18 panel.</p> <p>19 The core participants we are privileged to represent 20 have, over decades, campaigned for the protection and 21 rights of infected haemophiliacs and all gave evidence 22 to the Archer Inquiry. They have devoted their time 23 and, in the absence of any public funding, have invested 24 significant financial resources to ensure that their 25 fight was not forgotten.</p> <p style="text-align: center;">Page 43</p>
<p>1 first, though, Sam Stein QC on behalf of those core 2 participants represented by Milners.</p> <p>3 Opening statement by SAM STEIN QC</p> <p>4 MR STEIN: The person who knows that the blood products that 5 they supply contain a high risk of infecting another 6 person with a disease, such as Hep B or C, or HIV, 7 commits the offence of inflicting grievous bodily harm 8 if the person does not immediately die. If the supplied 9 person dies as a consequence, it is murder. Those who 10 are part of the supply chain, when either supporting or 11 assuring such a supply with the requisite knowledge of 12 what they are doing, are guilty of conspiracy to murder.</p> <p>13 It is clear that those who are responsible for the 14 criminal infection of people through the supply of 15 contaminated blood should be prosecuted. Those people 16 who wiped out thousands of haemophiliacs and other 17 people should be made to pay for their crimes.</p> <p>18 In the United States, the scandal has been labelled 19 "The haemophilia holocaust". In the UK, over 4,500 20 haemophiliacs were given HIV and Hepatitis C by 21 treatments provided on the NHS, of which approximately 22 half have since died and thousands more human lives have 23 been destroyed.</p> <p>24 The haemophiliacs infected and killed died horribly. 25 Their lives made a sheer misery, their families broken</p> <p style="text-align: center;">Page 42</p>	<p>1 Peter Mossman, a haemophiliac infected with HCV in 2 1985, who, having previously been an active member of 3 the Haemophilia Society North West, jointly formed the 4 Manor House Group in 1994, and who has since played an 5 important role in lobbying Parliament and protesting on 6 behalf of infected haemophiliacs. Having left the Manor 7 House Group, he today continues his campaign work 8 despite significant health problems.</p> <p>9 Colette Wintle, a woman with haemophilia infected 10 with Hepatitis C in Scotland in 1976, Hepatitis B in 11 Kent in 1982, and again with Hepatitis C at the Royal 12 Free Hospital in London in 1985.</p> <p>13 Colette lost her career in nursing due to 14 Hepatitis B infection, but also subsequently lost her 15 career in the airlines due to the sole fact that she was 16 a haemophiliac.</p> <p>17 Colette was also exposed to vCJD in 1993, a fact 18 that was shockingly withheld from her until 2004.</p> <p>19 Since 1994 she has actively researched and 20 campaigned for justice. Colette's husband, 21 Stephen Wintle, who has campaigned with her and, on one 22 occasion, wore a necklace of blood bags around his neck 23 outside of The Ministry of Health, who, other than 24 working with her on her campaign work, also fulfils the 25 role of her primary carer and works to provide for them</p> <p style="text-align: center;">Page 44</p>

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<p>1 both and their daughter.</p> <p>2 We also represent Carol Grayson, the sister-in-law</p> <p>3 of Stephen, a haemophiliac, who died of HIV, HCV in</p> <p>4 1986, and the widow of her haemophiliac husband,</p> <p>5 Peter Longstaff, who was also co-infected with HIV and</p> <p>6 Hepatitis B and C, and exposed to vCJD. Peter passed</p> <p>7 away in 2005.</p> <p>8 Following the death of her husband, Carol researched</p> <p>9 and wrote an acclaimed dissertation on contaminated</p> <p>10 blood, in 2006. That dissertation critiqued the</p> <p>11 findings of the now discredited government report,</p> <p>12 "Self-sufficiency in blood products in England and Wales</p> <p>13 from 1973 to 1991", published by the Department of</p> <p>14 Health in 2006.</p> <p>15 Her research revealed previously unpublished</p> <p>16 documents that had been allegedly destroyed or lost,</p> <p>17 which exposed glaring omissions and inaccuracies whilst</p> <p>18 pointing towards a government led cover up.</p> <p>19 Let me not forget Matthew Johnson, a witness to this</p> <p>20 Inquiry, a haemophiliac infected with Hep C and exposed</p> <p>21 to vCJD.</p> <p>22 For all four of our core participants, and</p> <p>23 undoubtedly all of those infected and affected by</p> <p>24 contaminated blood products, the gravity of this long</p> <p>25 overdue public Inquiry cannot be underestimated.</p> <p style="text-align: center;">Page 45</p>	<p>1 treatment of haemophiliacs, correctly asserted that this</p> <p>2 was the worst medical treatment disaster in the history</p> <p>3 of the NHS.</p> <p>4 So, this Inquiry is dealing with a double disaster</p> <p>5 of whole blood cases, and what appears to be the</p> <p>6 targeting of the haemophiliac community, but both cases</p> <p>7 must be fully investigated by the Inquiry.</p> <p>8 Now, sometimes the two groups will require different</p> <p>9 considerations, different experts and evidence. We</p> <p>10 suggest that always addressing the two groups together</p> <p>11 without careful thought will confuse the public's</p> <p>12 understanding of the issues. The different facts which</p> <p>13 apply to each group already confuses the media, with</p> <p>14 many stories having been published with incorrect or</p> <p>15 misleading facts. This is a disservice to both cases.</p> <p>16 The education and understanding of the public of the</p> <p>17 issues and medical conditions are fundamentally</p> <p>18 important, particularly considering the unjust</p> <p>19 stigmatisation and discrimination of the haemophiliac</p> <p>20 community in the past.</p> <p>21 Therefore, we ask that where it is possible and</p> <p>22 where there are, Sir, separate issues to be addressed,</p> <p>23 that haemophilia and whole blood issues are separated.</p> <p>24 We submit that dealing with the Inquiry and these issues</p> <p>25 this way would also provide some assistance to the</p> <p style="text-align: center;">Page 47</p>
<p>1 By 1991, the Minister for Health,</p> <p>2 Virginia Bottomley, had recognised what she termed the</p> <p>3 "special status of haemophiliacs". This was because she</p> <p>4 appreciated that a haemophiliac sufferer in the 1970s</p> <p>5 and 1980s already faced a battle against a lifelong</p> <p>6 condition that adversely affected their health. It also</p> <p>7 affected schooling, employment, insurance, travel and</p> <p>8 mortgage prospects, amongst other restrictions.</p> <p>9 If they survived the fight against the condition,</p> <p>10 then these issues had been grossly exacerbated by</p> <p>11 infected blood. The recognition of the special status</p> <p>12 of haemophiliacs was also because haemophiliacs have</p> <p>13 often been infected with multiple viruses, and multiple</p> <p>14 members of their families have been infected and killed.</p> <p>15 The factor concentrates provided to haemophiliacs</p> <p>16 carried such a high risk of infection that, even if you</p> <p>17 are lucky enough to avoid infection once or twice or</p> <p>18 more times, eventually, with blood sometimes carrying</p> <p>19 a 50 to 70 percent chance of transmitting a disease, you</p> <p>20 were going to be infected.</p> <p>21 The fact that only about half of haemophiliacs who</p> <p>22 were exposed to infected blood are alive today speaks</p> <p>23 for itself.</p> <p>24 Over recent days we have been reminded of the words</p> <p>25 of Lord Winston, who, in reference to the disastrous</p> <p style="text-align: center;">Page 46</p>	<p>1 respective members of the groups in allowing them to</p> <p>2 believe and see that their issues are understood. It</p> <p>3 will have the advantage of allowing for a better ability</p> <p>4 for people to live and work, and focus their attention</p> <p>5 on the parts of the Inquiry for which they have the most</p> <p>6 concern.</p> <p>7 I turn now to paragraph 1 of the terms of reference,</p> <p>8 and the question that we suggest that there is a need to</p> <p>9 investigate from 1950 onwards, but this must be done in</p> <p>10 a proportionate and careful way. The terms of reference</p> <p>11 have provided a solid foundation for the Inquiry to</p> <p>12 begin what will be a sizeable task.</p> <p>13 However, noting that paragraph 1 of the terms of</p> <p>14 reference state:</p> <p>15 "The Inquiry will examine the circumstances in which</p> <p>16 men, women and children treated by the NHS in the UK</p> <p>17 were given infected blood and infected blood products,</p> <p>18 in particular since 1970."</p> <p>19 We suggest that if the Inquiry is to properly</p> <p>20 investigate what happened and why, the questions of</p> <p>21 precisely who knew what and when, need to be answered.</p> <p>22 We believe that failing to adequately investigate what</p> <p>23 was known prior to 1970 would be a mistake. What we</p> <p>24 suggest and what we suggest is required is a settled</p> <p>25 foundation or platform of what was known and what</p> <p style="text-align: center;">Page 48</p>

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<p>1 warnings there had been, prior to 1970, about the danger 2 of collecting blood from contaminated sources. It was 3 recognised in the 1930s that a virus from a blood donor 4 could be transmitted to a recipient of blood or blood 5 products. 6 The potential problem of Hepatitis B began to be 7 appreciated only shortly before World War II ended. 8 During the Korean War of 1950 to 1953, a plasma 9 programme that had been developed by the United States 10 was discontinued because of the alarming percentage of 11 Hepatitis in service personnel who had received plasma 12 infusions, especially where the plasma had been prepared 13 from large pools. 14 Outbreaks of Hepatitis in haemophiliacs in the US, 15 from first exposure to factor concentrates, are known to 16 have occurred in the early 1960s. Importantly, in 1966 17 the eminent American professor of surgery, 18 J Garrett Allen, published his findings in the peer 19 reviewed medical journal of Surgical Science and 20 Practice of the Annals of Surgery. He said this: 21 "The most practical method of reducing the hazards 22 of Hepatitis B from blood is to stop using blood from 23 prison and [the term he used] also Skid Row donors." 24 We therefore feel that it is essential that the 25 Inquiry covers the period prior to the introduction of</p> <p style="text-align: center;">Page 49</p>	<p>1 points from more debatable references. The handling of 2 documents in this Inquiry is going to be dealt with by 3 a company called Relativity, using their systems. The 4 question of whether the documents held by this Inquiry 5 can be hyperlinked to the timeline should be considered. 6 But, in any event, each reference must be accompanied by 7 the Inquiry document reference term. 8 We suggest that the use of a living and growing 9 timeline will help the Inquiry to come to the 10 conclusions as to who knew what and when, and who was at 11 fault. And where criminal actions have been found and 12 identified, this Inquiry must not hesitate to refer the 13 matter to the DPP. 14 Paragraph 3 of the terms of reference. We welcome 15 paragraph 3 of the terms of reference and the commitment 16 to examine what other diseases people may have been 17 exposed to. It must be highlighted that haemophiliacs 18 have been infected with HIV, the full range of Hepatitis 19 viruses, paravovirus and exposed to vCJD. The Inquiry 20 must utilise the latest expert research and analysis to 21 establish what else infected blood has exposed the 22 victims to and what medically can be done to help them. 23 We invite the Inquiry to specifically establish the 24 number of haemophiliacs who have been exposed to vCJD, 25 examine how this compares proportionately with instances</p> <p style="text-align: center;">Page 51</p>
<p>1 factor concentrates to the UK in 1973, so as to properly 2 establish what was known in relation to the dangers of 3 Hep A, B and the risk of pooling plasma and when it 4 became known. 5 We suggest that considering what we know had been 6 identified by the end of the Korean War, that 1950 would 7 be the most appropriate start date from which to 8 determine what was already understood by 1970 onwards. 9 The most effective and economical way for this to be 10 done will be for the Inquiry to provide a timeline or 11 chronology of relevant dates and facts. 12 There have already been timelines produced by 13 campaigners which can assist. A detailed chronology 14 showing the correspondence, the published research 15 materials and warnings, the various media reports and 16 investigations and correspondence charted against the 17 known activities of companies producing and pooling the 18 infected plasma, and against the various medical and 19 political pronouncements, will provide this Inquiry with 20 a backbone of facts from which to draw its conclusions 21 and make recommendations as to change. 22 Of course, this timeline can only be populated, 23 filled in, by the Inquiry, who will need to act as 24 a gatekeeper for references to be included. We will 25 need to develop a system to differentiate hard facts and</p> <p style="text-align: center;">Page 50</p>	<p>1 of exposure in those receiving whole blood transfusions, 2 and whether there is any malign reason why exposure 3 amongst haemophiliacs was proportionately greater. 4 Sadly, it seems to us, that we have not yet seen the 5 full crisis of vCJD. 6 Consent, paragraph 6 of the terms of reference. The 7 Inquiry will of course examine the issue of consent. 8 The Nuremberg Code deals with consent to human 9 experimentation. Paragraph 1 from The Nuremberg Code 10 states: 11 "The voluntary consent of the human subject is 12 absolutely essential." 13 Reading onwards: 14 "This means that the person involved should have 15 legal capacity to give consent, should be so situated as 16 to be able to exercise free power of choice without the 17 intervention of any element of force, fraud, deceit, 18 duress, overreaching or other ulterior form of 19 constraint or coercion, and should have sufficient 20 knowledge and comprehension of the elements of the 21 subject matter involved so as to enable him to make an 22 understanding and enlightened decision." 23 The Hippocratic Oath for doctors, taken, or at least 24 in theory held dear by doctors, states: 25 "I will utterly reject harm and mischief."</p> <p style="text-align: center;">Page 52</p>

<p>1 The least any patient should expect before 2 undergoing any treatment, let alone experimental 3 treatment, is to feel safe in the knowledge that they 4 have been allowed to make an informed decision to 5 undergo that treatment with the full knowledge of the 6 potential risks and consequences of that treatment. 7 The last thing any human being should become is an 8 unwitting guinea pig or lab rat, but that is precisely 9 what happened to haemophiliacs. 10 The fact that haemophiliacs were targeted and used 11 as unwitting test subjects was communicated in a letter 12 discovered and preserved by Carol Grayson, dated 13 11 January 1982, to all Haemophilia Centre Directors 14 from the Oxford Haemophila Centre. 15 In a test of our technical ability, we will try and 16 show the relevant passage on the screen, if Henry 17 upstairs can provide it. 18 That reads: 19 "Although initial production batches may have been 20 tested for infectivity, by injecting them into 21 chimpanzees, it is unlikely that the manufacturers will 22 be able to guarantee this form of quality control for 23 all future batches. It is therefore very important to 24 find out, by studies in human beings, to what extent the 25 infectivity of the various concentrates has been</p> <p style="text-align: center;">Page 53</p>	<p>1 Hep C and HIV. There are identifiable conflicts of 2 interest, particularly for doctors in the NHS with 3 decision-makers believed to have been on the payroll of 4 pharmaceutical companies, who were providing the NHS 5 with infected blood products and funding research, all 6 whilst maximising profit from the exploitation of 7 haemophiliacs. 8 This warrants specific interrogation and 9 investigation, and any who benefited financially must be 10 exposed. 11 The clear repeated and unacceptable breaches of The 12 Nuremberg Code and The Hippocratic Oath must be fully 13 investigated, and those responsible identified and 14 brought to justice. 15 Yesterday, we witnessed an incredibly moving 16 commemoration. So many people have died and so many 17 people's lives have been lost. For the survivors, their 18 lives have been devastated and entirely consumed. 19 Chair, you stated yesterday that you want to put people 20 at the heart of the Inquiry, and that in order to do so 21 during the first three months and final period of the 22 Inquiry you will hear from the infected and affected. 23 The Inquiry needs to hear from those who have been so 24 infected and so affected, and needs to hear the evidence 25 they can provide about events, which are central to the</p> <p style="text-align: center;">Page 55</p>
<p>1 reduced. The most clear cut way of doing this is by 2 administering those concentrates to patients requiring 3 treatment who have not been previously exposed to large 4 pool concentrates. Those patients are few in number, 5 but a study along these lines is being carried out at 6 Oxford to determine the infectivity of Factor 8 7 concentrates produced by the Plasma Fractionation 8 Laboratory, Oxford, and Blood Products Laboratory, 9 Elstree. This study shows that it is possible to 10 demonstrate infectivity using quite small numbers of 11 previously untreated patients." 12 Truly, awfully shocking. 13 Thank you. 14 We now know that there was non-consensual testing of 15 blood and organs of haemophiliacs, withholding of test 16 results from patients who had been infected or exposed 17 to disease, who were being tested without their 18 knowledge. There was destruction and withholding of 19 medical records that evidenced what each individual had 20 been tested and treated for, and the inaccurate 21 recording of statistics, including deaths of 22 haemophiliacs exposed to infected blood. 23 Documents have been uncovered that provide evidence 24 that government ministers gave their approval to the 25 surveillance of haemophiliacs who had been infected with</p> <p style="text-align: center;">Page 54</p>	<p>1 understanding of the facts that are crucial to the core 2 of this Inquiry. 3 Other inquiries have allowed core participants to 4 present what were called "pen portraits" or, as I prefer 5 to call them, personal commemorations of people's lives 6 and deaths. Within this Inquiry, under the terms of 7 reference, paragraph 4, page 3 onwards, the Inquiry is 8 committed to considering the impact of infection from 9 blood or blood products on people who are affected and 10 on partners, children, parents, families, carers and 11 others closer to them. As counsel to the Inquiry, 12 Ms Richards Queen's Counsel said yesterday, "The Inquiry 13 is to consider all of the impact on people's lives". 14 This aspect of the Inquiry is very important and the 15 need to commemorate the lives lost and the parts of 16 lives that have been wasted and re-routed through 17 infection has an important impact on the Inquiry's 18 overall determination. The determination that we 19 suggest that this is directed to is that this must never 20 happen again and, secondly, that there must be, from 21 that evidence, an accurate assessment of the extent and 22 amount of financial support and compensation that should 23 be considered in the future. 24 We need to think and address the question of how can 25 this be best done, when, Sir, as you pointed out, that</p> <p style="text-align: center;">Page 56</p>

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<p>1 there is also a sad need to complete this Inquiry in 2 a timely fashion.</p> <p>3 What we ask is this: that real latitude is given to 4 those giving evidence concerning the impact on their 5 lives and the lives of those who have been lost in order 6 to properly present their evidence in this regard. To 7 achieve this goal, we suggest that there will be a need 8 to discuss the impact section of the evidence with 9 counsel to the Inquiry, the solicitor to the Inquiry and 10 the need, potentially, to provide a presentation which 11 might include evidence or photographs, films or 12 documents to be shown on a screen.</p> <p>13 And so time will need to be provided at the 14 beginning of any such evidence, so that can be dealt 15 with properly and with dignity.</p> <p>16 Paragraph 9(a) of the terms of reference recognises 17 that there is a real and identifiable issue as to the 18 extent to which there have been wilful attempts to 19 conceal the truth of what was known and what has 20 happened. We say that there was a systematic attempt to 21 destroy evidence, avoid the truth and thereby abdicate 22 responsibility for the actions of the state and its 23 representatives.</p> <p>24 We know that documents that ought to have been kept 25 and stored in the National Archives have been destroyed</p> <p style="text-align: center;">Page 57</p>	<p>1 our written submissions setting out our proposals.</p> <p>2 The Inquiry needs, when dealing with the question of 3 core participant support, to ensure that there are 4 discussions with core participants. Every effort must 5 be made to ensure that the needs of infected and 6 affected families are put first in this Inquiry. Of 7 course, this includes thought that must be given for the 8 provision of support, childcare at Inquiry hearing days. 9 Accessibility issues must be addressed, not only at the 10 chosen venue for hearings, but also through the 11 provision of IT equipment and continuing IT support, to 12 enable those who can't attend in person due to their 13 health and who cannot otherwise afford such equipment 14 are able to observe the Inquiry hearings.</p> <p>15 We also need to recognise that when it comes to the 16 provision of evidence that video link systems may well 17 be required.</p> <p>18 Paragraph 11 of the terms of reference deals with 19 the question of interim recommendations. We welcome the 20 specific scope for the Inquiry to make interim 21 recommendations, referred to in the terms of reference. 22 We say it is entirely appropriate for the Inquiry to 23 make interim recommendations as soon as it possibly can, 24 particularly considering the financial plight of 25 infected and affected haemophiliacs and the fact that</p> <p style="text-align: center;">Page 59</p>
<p>1 or have gone missing. We know from the experience of 2 Carol Grayson that she provided documents to the 3 government to plug the gap in the archives that was said 4 to be irretrievably lost and that, since then, the 5 documents she provided have since been held out to be 6 newly discovered. There will no doubt be other infected 7 or affected persons who hold documents or copies of 8 documents that have been destroyed or lost according to 9 official records.</p> <p>10 Due to the distrust of the government and public 11 bodies, such as the NHS, there is understandably a deep 12 sense of suspicion as to what will befall documents that 13 are released the Inquiry. This may give genuine cause 14 to question whether to release those vital documents at 15 all. This must be avoided, particularly if an accurate 16 timeline is to be established so that we know who knew 17 what and when. Therefore, we call on the Inquiry to 18 establish a documents protocol, to ensure that original 19 documents in the hands of survivors are not lost and 20 that, in the spirit of openness and to fulfil the duty 21 of candour for this Inquiry, there is a record made on 22 copied documents and a referencing facility provided to 23 ensure we know exactly who has produced each document to 24 the Inquiry and when.</p> <p>25 We will of course provide more detailed points in</p> <p style="text-align: center;">Page 58</p>	<p>1 many have died waiting for this Inquiry.</p> <p>2 The advantage of an Inquiry that inevitably takes 3 some time is that the life-span of the Inquiry can be 4 used to both make interim recommendations and follow 5 through those recommendations by considering how the 6 recommendations are dealt with by the state through to 7 action.</p> <p>8 Targets for interim recommendations would include 9 compensation and the current support payment schemes. 10 We ask that you, Sir, reach out to government and 11 request that they undertake, through the DWP, not to 12 carry out any further reassessments of the England 13 Infected Blood Support Scheme, EIBSS, payments for the 14 duration of this Inquiry.</p> <p>15 In due course, we will seek a recommendation of 16 benefits passporting for haemophiliacs, in line with the 17 recommendations made by the Archer Inquiry, but there 18 can be no good reason why the infected and affected 19 should have to suffer the ignominy of having to jump 20 through unnecessary procedural hoops to receive basic 21 entitlements in what the final report of the 22 Archer Inquiry labelled an "undeserved affront to their 23 dignity".</p> <p>24 We suggest the Inquiry reviews, as part of its 25 possible interim recommendations, the disparity in</p> <p style="text-align: center;">Page 60</p>

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<p>1 support payments made across the UK and the inadequacy 2 in particular in support in England for widows and 3 widowers. 4 Acknowledgement should be made that after their 5 loved ones are infected by the actions or inactions of 6 the government many gave up their careers or could only 7 enjoy limited careers because of the need to care for 8 their infected partners. 9 As to current support payments and their assessment, 10 there is a complete departure in England through EIBSS 11 at least, from the principle at paragraph 3, page 13 of 12 the 1991 settlement leading to the MacFarlane Trust that 13 payments under that scheme and therefore its successor, 14 EIBSS, should be excluded from consideration in the 15 assessment of social security or statutory benefits. 16 We also need to resolve the current and gross 17 unfairness of ongoing payments across the English and 18 Scottish borders and across the sea to Ireland. We 19 suggest that the factors which have led to these payment 20 inequalities be the subject of a timetable for written 21 submissions, responses and a dedicated period set aside 22 to hear representations to resolve these issues sooner 23 rather than later and dealt with by interim 24 recommendations. 25 Given the urgency of the situation facing the</p> <p style="text-align: center;">Page 61</p>	<p>1 at least belatedly, the state through this Inquiry has 2 thoroughly investigated this tragedy and make 3 recommendations to ensure that nothing of the like ever 4 happens again. 5 Now, this Inquiry has started over these two days 6 with a real display of determination and goodwill, 7 a film I remember many years ago described as positive 8 waves. Working with Peter, Colette, Stephen and Carol 9 we will all strive to support and where required, Sir, 10 push the Inquiry in the pursuant of its mandatory 11 objectives. 12 Finally, let us not forget that after Archer and 13 Penrose this for our CPs and for many others is the 14 third Inquiry into this disaster. That means, we 15 suggest, that we must work together to make this the 16 last Inquiry. So those are our submissions. 17 SIR BRIAN LANGSTAFF: Thank you very much indeed, Mr Stein. 18 Now for Ms Karon Monaghan Queen's Counsel who 19 represents the core participants who have instructed 20 Hudgell Solicitors. 21 Opening statement by Karon Monaghan QC 22 MS MONAGHAN: Thank you, Sir. Yes, as you have said, my 23 name is Karon Monaghan, I represent four core 24 participants, along with Mr Philip Dale and Ms Cyrilia 25 Knight of Hudgell Solicitors.</p> <p style="text-align: center;">Page 63</p>
<p>1 infected and affected members of the Haemophilic 2 community, we also seek a recommendation for the payment 3 of compensation. We remind you of the important 4 statements made in the final report of the 5 Archer Inquiry with regard to the duty of government. 6 The very purpose of government is to protect its 7 citizens so far as possible from life's vicissitudes and 8 to afford them the best quality of life. Where poverty 9 is widespread even though not universal among a limited 10 and readily defined category of citizens, and 11 particularly where it is attributable to a specific 12 misfortune, we believe that they are entitled to look to 13 the government for redress. 14 The government has an immediate duty to step up, 15 protect its citizens and to provide the financial 16 recompense that infected and affected members of both 17 groups deserve. 18 In conclusion, it is obvious that the Inquiry can't 19 turn the clock back for the victims but it must 20 establish the truth behind this terrible atrocity. The 21 medical profession must wake up to what has happened and 22 people must be treated with respect. Once this Inquiry 23 is complete there must be an apology from the state 24 which acknowledges all that has happened. Everyone 25 needs to find some measure of peace from the knowledge,</p> <p style="text-align: center;">Page 62</p>	<p>1 As in the case of others we have heard from today, 2 this statement has not been prepared by the lawyers 3 alone, but has been prepared together with our four 4 clients. Our clients contracted HIV in the early 1980s 5 through contaminated blood products used in the 6 treatment of their haemophilia. At the time this 7 diagnosis was revealed to each of them one was a young 8 boy, the others were young men. They were all later 9 informed of infection with Hepatitis C too. 10 With the exception of the youngest, our clients have 11 all been involved with the call for this Inquiry as well 12 as with other support work in their community over many 13 years. They are four friends and share a deep interest, 14 not just in a rigorous investigation, but in particular, 15 in one that is alive to the equality and human rights 16 implications of the decisions made before, during and 17 after this disaster, something I'll come back to in one 18 moment. 19 Their experiences, including those gained through 20 their campaigning work, are such that they have now 21 acquired considerable knowledge and experience and 22 expertise in the matters that are to be the subject of 23 this Inquiry, and they want to deploy that expertise to 24 assist this Inquiry in its important work. 25 Starting then, Sir, with the first matter you raised</p> <p style="text-align: center;">Page 64</p>

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<p>1 yesterday: what are the issues of most importance to my 2 clients? The principal questions that our clients want 3 answered are simple. They want to establish once and 4 for all what happened, when it happened, how it 5 happened, why it happened, who was or is responsible, 6 how have those affected and infected been supported 7 since and what are the continuing risks to those who 8 have or may have been exposed to other infections 9 including vCJD.</p> <p>10 They also want the findings that emerge from this 11 Inquiry to underpin recommendations directed at ensuring 12 that catastrophic events of the sort that happened here 13 by the transmission of pathogens and poisons through 14 medical treatments are never repeated.</p> <p>15 As a starting point, our clients consider that this 16 Inquiry will need to establish what system of 17 pharmacovigilance existed at relevant times. The 18 examination of the use of Factor 8 is critical to our 19 clients. They need to know what formal systems existed 20 to monitor its use and to have examined how, if at all, 21 concerns about it were addressed.</p> <p>22 The Inquiry must also ascertain what information was 23 given to the Blood Transfusion Service and to 24 pharmaceutical companies, in particular in the period 25 from July 16, 1982, the date from when in all likelihood</p> <p style="text-align: center;">Page 65</p>	<p>1 concentrates? Since Factor 8 was very much seen as the 2 wonder treatment by many haemophilia doctors, as indeed 3 was alluded to yesterday, there's real concern by my 4 clients that doctors may have felt inclined to ignore 5 the risks or downplay them because of the benefits 6 believed to derive from Factor 8.</p> <p>7 Our clients are also mindful that in the 1970s and 8 80s there was government awareness of the need for UK 9 self-sufficiency in blood and blood products, something 10 again already referred to. Why then did the UK resort 11 to commercially obtained sources overseas?</p> <p>12 This Inquiry, our clients say, will need to unpack 13 the government's actions and inactions that stymied 14 efforts towards UK self-sufficiency or unpick what 15 Lord David Owen, Health Minister at the time, told the 16 Archer Inquiry was resistance in the department to go 17 for self-sufficiency. He said he suspected that it was 18 the deep financial pressure they were coming under in 19 respect of the Health Service budget. My clients want 20 those pressures to be unpicked and explored and for 21 judgments to be made about them.</p> <p>22 There's evidence, for example, that in the 23 Netherlands early warning signs were heeded. They 24 became self-sufficient and in consequence relatively few 25 patients with haemophilia in the Netherlands contracted</p> <p style="text-align: center;">Page 67</p>
<p>1 it became clear, based on the available medical 2 evidence, that people with haemophilia were at risk of 3 contracting what later became known as HIV through blood 4 products. So from the period commencing July 16, 1982 5 until the introduction of HIV testing and heat treated 6 Factor 8.</p> <p>7 Documents which shed light on the understanding in 8 government about this risk and what they were told about 9 it by pharmaceutical companies must be disclosed. 10 I will come back to documents in due course.</p> <p>11 A crucial question too is whether there were 12 incentives from pharmaceutical companies for doctors or 13 the haemophilia centres to off-load what were cheap and, 14 in the event, infected products despite risks. Risks 15 from Factor 8 usage appeared to have been decidedly 16 played down. People with haemophilia were told that 17 conceivable risk to health would be more serious if they 18 didn't take Factor 8. Factor 8 usage was then actively 19 promoted. These matters need to be explored thoroughly.</p> <p>20 Since there was heavy reliance too on the experience 21 of haemophilia doctors in monitoring the use of factor 22 concentrates, it will also be important to explore 23 existing records that depict the state of knowledge of 24 treating doctors at the time. Were they aware of 25 hepatitis risk or unknown pathogens in factor</p> <p style="text-align: center;">Page 66</p>	<p>1 HIV as a result of infected blood products.</p> <p>2 It seems too that in the United Kingdom an 3 artificially high evidential bar was set, so legitimate 4 concerns about risks related to Factor 8 were regarded 5 as insufficient to justify action. Our clients want to 6 know why it took so long to identify and convey the 7 actual risks of the transmission of HIV, for example.</p> <p>8 There was the infamous "Haemofact" leaflet that many 9 of you will recall which suggested that the risk of HIV 10 infection for people with haemophilia was 1 in 1,000. 11 Haemophilia doctors, Blood Transfusion Services and the 12 Department of Health seemed to struggle to come to terms 13 with and to communicate the grim reality of HIV 14 infection to those who were regarded as innocent 15 haemophilia victims. The difficulty in coming to terms 16 with this seemed to trigger a strain of denialism in 17 some doctors.</p> <p>18 For our clients, this raises questions of stigma and 19 anti-gay prejudice and pathologising of gay men and 20 intravenous drug users. The question has to be asked 21 why such a high evidential bar was set by senior 22 haemophilia doctors in identifying the risk of HIV 23 transmission for their patients. Were they themselves 24 unconsciously thinking of those with haemophilia as the 25 innocents, unlike the guilty, the gay men, the</p> <p style="text-align: center;">Page 68</p>

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<p>1 intravenous drug users, those people with HIV, who 2 suffered the gross stigma and prejudice associated with 3 HIV in the 1980s? 4 What the government and the NHS ought to have done 5 to remove the stigma associated with HIV status is 6 a question that touches closely on the experiences of 7 those people with haemophilia, those people who were 8 infected by reason of their haemophilia, but it touches, 9 too, upon the experiences of all of those who were 10 diagnosed as HIV positive at the time. Gay men and 11 others with whom my clients have stood in solidarity 12 over the years. 13 Our clients then resist any narrative of haemophilia 14 exceptionalism, as it is sometimes described. Their 15 concern is for an Inquiry that robustly asks and 16 enquires into those matters that form the subject of the 17 terms of reference for this Inquiry, but they do not 18 seek to distinguish themselves as more deserving of 19 sympathy or of support than those who contracted HIV 20 through sex, intravenous drug use or otherwise, and the 21 same is true of HCV. 22 At the core of the grave misapprehension around 23 risk, then, is an issue of equality. In the early 24 1980s, AIDS was considered the gay plague and associated 25 with the perceived debauchery of gay men in New York and</p> <p style="text-align: center;">Page 69</p>	<p>1 provision for counselling following an HIV or 2 Hepatitis C positive diagnosis. HIV clinics were mainly 3 populated by gay men and Hepatitis C clinics by 4 intravenous drug users. The label of those who 5 contracted HIV or Hepatitis C as a result of their 6 haemophilia, as innocent victims, didn't help with their 7 integration into the broader HIV, Hep C positive 8 community. Infected people who survived often tell 9 a story of having to educate themselves about their 10 co-infections, and sometimes their doctors, too, along 11 with other healthcare providers. In the case of our 12 clients, the process of self-education forced them to 13 integrate into the wider HIV community, in particular 14 among gay men and other at risk groups. It is that 15 experience, generally a very positive experience, which 16 informs their approach to this Inquiry. Respect for the 17 dignity of all infected or affected by HIV and HCV. 18 Some of our clients were tested for both HIV and HCV 19 without their knowledge or consent and, like many 20 others, were not even aware of the results for a time. 21 In 1991, when the Hep C testing of people with 22 haemophilia was conducted, many did not know that they 23 had been identified as Non A - Non B Hepatitis positive 24 or the ramifications of their test results. 25 Concerns about communication and the delivery of</p> <p style="text-align: center;">Page 71</p>
<p>1 San Francisco. The tendency to ignore or underestimate 2 the risk associated with the use of Factor 8, 3 effectively by requiring incontrovertible proof, often 4 reflected, our clients say, a state of disbelief that 5 haemophilia, the wonder drug for haemophilia, could 6 actually be the purveyor of what was considered a gay 7 plague. The extent to which this was a psychological 8 blind spot that affected the approach to risk must be 9 examined by this Inquiry. 10 Then there was after the diagnosis. There were long 11 periods where there were few advances in the treatment 12 of HIV and Hepatitis C and then periods of massive 13 advancement. For HIV, there was huge progress, in 14 particular between 1995 and 2000, when highly active 15 antiretrovirals therapy for HIV appeared and, in the 16 case of Hepatitis C, between 2014 and 2017, with direct 17 acting antiretrovirals. How quickly and how well was 18 information about these advances and improvements made 19 available to people co-infected with haemophilia, HIV 20 and HCV? That's a question, too, that must be examined 21 by this Inquiry. 22 My clients know that obtaining accurate information 23 about infection was a massive problem for those infected 24 by contaminated blood products. 25 In addition, in the early 1980s, there was no</p> <p style="text-align: center;">Page 70</p>	<p>1 information are obviously relevant, both for the 2 question of support, but also under the topic of 3 consent, as well. 4 In scrutinising the support given to those infected 5 or affected, the Inquiry should also examine the 6 indignities dumped upon those infected by the need to 7 apply for discretionary payments or welfare benefits, 8 and then subject themselves to intrusive and sometimes 9 demeaning questioning about their lives and the 10 seriousness of the impact of their infections upon them. 11 For our clients, too, the shameful lack of 12 transparency around these events is of great importance 13 and must be robustly explored, with the reasons for that 14 lack of transparency interrogated. The absence of 15 candour and openness by the government and others, and, 16 frankly, what our clients believe can only be viewed as 17 a cover-up, must be examined and, again, those 18 responsible called to account. 19 The question, why has government resisted efforts to 20 find out what happened for so long? is an important one 21 for our clients and we say should be an important one 22 for this Inquiry. 23 This requires rigorous scrutiny of claims of lost 24 documents and public interest immunity, something I'll 25 touch upon very shortly.</p> <p style="text-align: center;">Page 72</p>

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<p>1 As to the future, our clients see this Inquiry as an 2 opportunity to develop recommendations directed at 3 better ensuring that not only do we have a system for 4 protecting our blood supply, but also that there are 5 safeguards against any future route for passing 6 pathogens, including presently unknown pathogens, from 7 one individual cell or organ to another person in the 8 case of treatment, while at the same time -- and very 9 importantly, not to be lost sight of -- not 10 inadvertently prohibiting the use of genetic treatments 11 for conditions such as haemophilia.</p> <p>12 They see this Inquiry, too, as an opportunity for 13 re-examining policies, practices and procedures for the 14 government handling, storing and, crucially, destroying 15 of documents relating to matters of great controversy. 16 In particular, where the risks of litigation or 17 political embarrassment loom large.</p> <p>18 Sir, yesterday, you also said that you saw the 19 opportunity for core participants to make opening 20 statements as one that could assist you when deciding 21 upon the shape of the Inquiry, including the procedures 22 to be adopted.</p> <p>23 On this, as a general approach, we invite the 24 Inquiry to adopt a human rights sensitive approach 25 throughout. I have touched upon the equality issues as</p> <p style="text-align: center;">Page 73</p>	<p>1 human beings with haemophilia. Persons with haemophilia 2 are not all they are.</p> <p>3 Further, and as to what our clients believe was 4 clearly a cover-up, it is our clients' view that there 5 must be an early demand of relevant government 6 departments to identify which documents were in fact 7 destroyed and describe the circumstances surrounding 8 their destruction; to explain the basis upon which 9 public interest immunity was sought to resist disclosure 10 in previous civil litigation, provide the Inquiry with 11 a schedule of material, if any, that it contends or the 12 government departments contends is non-disclosable by 13 reason of public interest immunity or legal professional 14 privilege; to explain their previous assertions that, on 15 the one hand, documents were destroyed and, on the other 16 hand, that those very same documents were 17 non-disclosable by reason of public interest immunity. 18 Did they, did those documents, do they still exist or 19 not?</p> <p>20 If not, why not? And if they do exist, why in the 21 case of some did the relevant government department say 22 they did not?</p> <p>23 Further still, this Inquiry should not be distracted 24 by the purported justifications found in the oft 25 repeated claims that what was done was the very best at</p> <p style="text-align: center;">Page 75</p>
<p>1 our clients see them and, in this context, we envisage, 2 for example, that it will be necessary to interrogate 3 assumptions and presumptions about HIV and AIDS, and 4 Hepatitis B and C, even though they may have been 5 conventional thinking in the 1970s and 1980s.</p> <p>6 Care must be taken, too, not to reinforce the stigma 7 of HIV and AIDS through the discourse in this Inquiry. 8 It will be necessary, too, to ask what role the 9 government thought its international obligations under 10 the European Convention on Human Rights had to play 11 throughout the period with which this Inquiry is 12 concerned. As you will know, Sir, the state, comprising 13 all the state agencies, was, and is, as a matter of 14 international law, under a duty to protect those known 15 to be facing a real and immediate risk to their lives, 16 and what of Article 8, which also is a matter of 17 international law bound the state, and its guarantee of 18 respect for private life, the family, human personality 19 and dignity.</p> <p>20 As to dignity and this Inquiry, in addition to the 21 matters I have also raised, with the greatest of respect 22 to everybody here, everybody who is touched by the 23 events leading to this Inquiry, for our clients language 24 is important. Our clients don't describe as 25 haemophiliacs. They self-identify as human beings,</p> <p style="text-align: center;">Page 74</p>	<p>1 the time and that, ultimately, more appropriate 2 decisions and actions would not have made any difference 3 in any event.</p> <p>4 As to the core participants, if this Inquiry is to 5 be effective and meet the aspirations of the core 6 participants and others who have been infected or 7 affected, it must be inclusive and allow for full and 8 proper participation, something that has been touched 9 upon by others today.</p> <p>10 You have set out your commitment, Sir, again today, 11 to achieving this and my clients have been very pleased 12 to hear this. But that commitment does mean ensuring 13 that advocates of the core participants have the chance 14 to speak to them and to make enquiries on their behalf. 15 It won't be enough, we say, to allow the core 16 participants' representatives a walk-on part, to allow 17 them simply to pass Post-it notes to counsel to the 18 Inquiry with suggested questions during examination of 19 the most important witnesses.</p> <p>20 Core participants, through their representatives or 21 by themselves where they are unrepresented, must be 22 permitted to ask questions that they want to ask in the 23 way that they want to ask them and trust must be 24 invested in them by the Inquiry that they will do so 25 responsibly, fairly and proportionately.</p> <p style="text-align: center;">Page 76</p>

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<p>1 Finally, as you have said, Sir, the infected and 2 affected must be at the forefront of this Inquiry. To 3 that end, I would like to finish our contribution today 4 by reading an extract from a statement made by one of 5 our clients and then make a short comment. He says this 6 about first being informed of his diagnosis of HIV, 7 contracted through treatment for his haemophilia: 8 "I was called into an office at the Royal Free 9 Hospital in 1984/5/6 while attending a routine 10 appointment for my bleeding disorder. In this room, 11 I was told my medical treatment had infected me with the 12 AIDS virus for which there was no treatment, no cure and 13 no prognosis, other than that everyone else who had been 14 infected died a horrible, slow and painful death within 15 two to three years of infection. I must have asked all 16 sorts of questions: how long have I got? When will 17 I become ill? Will there ever be a cure? None of them 18 could be answered, and the only piece of advice 19 I remember being told is to either not have sex or, if 20 I really had to, then to use two condoms. I'll never 21 forget walking up to Pond Street, to the nearest pub, 22 buying a pint and writing my will." 23 Sir, the spectre of death is a common theme in the 24 stories of those infected and affected by this scandal. 25 Many who campaigned for an Inquiry are no longer with</p> <p style="text-align: center;">Page 77</p>	
<p>1 us. Those who remain, including our clients, bear no 2 undiluted sense of triumph that this public Inquiry is 3 now a reality. They take comfort, however, from your 4 commitment, Sir, and the commitment of your legal team 5 to getting it right this time. They truly hope now for 6 justice. 7 SIR BRIAN LANGSTAFF: Ladies and gentlemen, that concludes 8 the proceedings for today. We start again at 10 o'clock 9 tomorrow morning, sharp, and I look forward to seeing 10 you then. 11 (4.30 pm) 12 13 14 15 16 17 18 19 20 21 22 23 24 25</p> <p style="text-align: center;">Page 78</p>	

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