1 Friday, 28 March 2012 2 (9.30 am) (Proceedings delayed) 3 (10.05 am)4 THE CHAIRMAN: Good morning. 5 6 Mr Di Rollo, you have to begin? 7 Submissions by MR DI ROLLO MR DI ROLLO: Thank you, sir. I think the first thing that 8 9 I have to do is to say something about our approach to 10 written submissions. As requested, by you, sir, we were required to make 11 12 written submissions which were to be with the Inquiry on 13 Monday of this week. We have made substantive submissions in relation to 14 15 most of the topics covered in the public hearings, 16 starting with the four deaths. 17 In relation to these, the submissions used the model of a determination under the Fatal Accidents and Sudden 18 19 Deaths Inquiry (Scotland) Act 1976. In relation to the 20 other topics, we have followed the structure set out by 21 you, sir, at the hearing on 13 October 2011. 22 The documents have been placed in court book and 23 I should indicate the numbers, I think, so that they can 24 be accessed from the transcript. 25 Our submission in respect of the four deaths: first

of all, <u>[PEN0190773]</u> is the Reverend David Black;
 <u>[PEN0190777]</u>, Mr Laing; <u>[PEN0190779]</u>, Mrs O'Hara and
 <u>[PEN0190783]</u>, Mr Tamburrini.

The list of issues for the patient interests is
[PEN0190806]. And our submissions in respect of those
are, in respect of B1, [PEN0190466], B2, [PEN0190476],
B4, [PEN0190552], B5 [PEN0190571], B6, [PEN0190593], C1,
[PEN0190600], C2, [PEN0190605]. C3A, [PEN0190657], C4,
[PEN0190712], C5, [PEN0190742] and C6, [PEN0190761].

10 Sir, we have attempted to answer the questions posed 11 in our issues. We have, of course, done so from the 12 perspective of patients, relatives and the Haemophilia 13 Society. What is stated is intended to provide the 14 Inquiry with a point of view in relation to the evidence 15 on these topics.

We have tried to be as thorough as we possibly can taking into account all of the material made available. Throughout, we have tried to support what is stated with references to the testimonies, statements and documents. We very much hope that the Inquiry will find our submissions of assistance in the preparation of the final report.

There are three topics in relation to which we have not made a submission. These are statistics and the two viral inactivation topics, B3 and C3.

Statistics is a topic that we would wish an
 opportunity to make a submission on once the Inquiry has
 made available all the material which will form the
 basis of its analysis.

In relation to B3 and C3, what I would like to say 5 is that it is of course in everyone's interests that 6 7 term of reference 12, "to report as soon as 8 practicable", is observed. We understand the need for 9 a tight deadline for the production of submissions by 10 the core participants, and as the deadline for submissions approached, we concentrated our efforts on 11 12 certain areas of particular concern.

I took the decision that it was not necessary to put in a response in relation to C3 and B3, having regard to the absence of any real controversy in the evidence on these topics during the public hearings. We have posed certain questions in the issues lodged by us, and I hope these provide an indication of some of the points to be considered by the Inquiry in the final report.

20 Before finishing, in relation to our submissions, 21 I think now would be an appropriate point, for my part, 22 and I think on behalf of the other core participants, to 23 thank the very exceptionally helpful treatment we have 24 received from those in charge of the documents, Neil, 25 Oliver and Keith, and also from the secretary and deputy

1 secretary of the Inquiry team, Maria and Sarah, and also 2 Margaret who looked after the witnesses. I would also like to thank, on behalf of the core participants, our 3 stenographers, Stuart and Catherine. 4 Thank you, sir. 5 THE CHAIRMAN: Yes, Mr Anderson? 6 7 Submissions by MR ANDERSON 8 MR ANDERSON: Yes, sir. In relation to the submissions, you 9 will be aware that I represent the interests of both the 10 SNBTS and also the Scottish health boards who, of course, employed the haemophilia clinicians at the 11 12 relevant time. 13 You will also be aware that, although I have had the 14 excellent support of the solicitors from the Central 15 Legal Office, I don't have a junior counsel. So the submissions, as you will no doubt appreciate, have been 16 17 divided up. I have been responsible for drafting those 18 19 submissions on behalf the health boards and a couple of 20 those on behalf of the SNBTS. The others within the SNBTS have been the work of individuals within that 21 22 organisation and have been vetted and revised by the 23 legal representatives. 24 The approach taken to the submissions was not to

4

answer every question posed by every core participant

but rather to seek to concentrate upon those areas where it was felt that there was the potential for some controversy, and in this regard we have taken the lead, largely but not exclusively, from the questions posed by Inquiry counsel and sought to answer those in a way that it is hoped will be of assistance to you in determining the final report.

8 I would simply seek to associate myself with the 9 sentiments expressed by my learned friend Mr Di Rollo in 10 thanking all those concerned.

11 THE CHAIRMAN: Mr Johnston?

12 MR JOHNSTON: Thank you, sir.

13 The Scottish Government submissions appear at

14 [PEN0190274].

15 THE CHAIRMAN: Mr Johnston, excuse me just a moment. It has 16 been drawn to my attention that Mr Anderson has not 17 followed the practice of reading in the numbers, and 18 that might be helpful, as Mr Di Rollo has done, in order 19 that people can link through to them. I am sorry for 20 interrupting you but we should get all of those. 21 MR ANDERSON: My apologies, sir. All the documents have the 22 preface "PEN019".

 23
 The introduction is [PEN0190355], issue one is

 24
 [PEN0190360], issue 2 is [PEN0190401], issue 3 and issue

 25
 4 are [PEN0190428]. Issue 5 is [PEN0190439]. Issue 6

1 is [PEN0190447] and the methodology of the collective 2 response is [PEN0190454]. And finally the list of issues is [PEN0190805]. 3 Submissions by MR JOHNSTON 4 THE CHAIRMAN: Mr Johnston, if I can start you afresh. 5 MR JOHNSTON: Thank you, sir. 6 7 I'll just repeat what I said, which is that the 8 Scottish Government submissions appear at [PEN0190274]. 9 In the written submissions the Government does not 10 attempt to address every issue raised by the Inquiry team but it does try to cover all of those that 11 12 particular affect the government as a core participant. 13 So for that reason, the introduction deals with the 14 administrative structures that were in place for 15 obtaining advice and formulating policy and guidance, and for providing the necessary resources to the 16 17 Scottish National Blood Transfusion Service. In addition, the introduction deals with the 18 19 standard of scrutiny that it is thought appropriate for reviewing decisions that were taken in the reference 20 21 period for the Inquiry. 22 So far as the specific topics that have been 23 investigated are concerned, the Government submissions 24 follow the order of the topics which the Inquiry team 25 identified. Here, they don't attempt to grapple with

1 the difficult issues of science and medicine, or to 2 enter into questions that are thought to be properly matters between doctor and patient, but rather they 3 focus on issues that particularly affect the Government, 4 such as the provision of necessary support and resources 5 6 for the blood transfusion service and the way in which 7 policy was formulated and communicated. 8 So I hope, beyond that, the submissions can speak 9 for themselves, and I would simply like also to associate ourselves with the thanks that Mr Di Rollo 10 expressed earlier. 11 12 THE CHAIRMAN: And you have a single document that you have 13 given the reference number for? 14 MR JOHNSTON: Yes, that's correct. 15 THE CHAIRMAN: Thank you very much. 16 Mr Di Rollo, we move to the second phase of today's 17 business, when you have the opportunity to make a closing statement. 18 19 Submissions by MR DI ROLLO 20 MR DI ROLLO: Thank you, sir. 21 On behalf of the patient and relative core 22 participants and on behalf the Haemophilia Society, I would like to make some remarks at the conclusion of 23 24 the public hearing phase of this Inquiry. The first matter I would like to address is the need 25

for this process. The process that we have been engaged
 in is designed to provide answers to questions
 concerning a very complicated series of events that
 occurred over many years from at least 1974 right up
 until the present day.

Countless hours have been devoted to considering 6 7 a truly awesome quantity of material. There should be 8 no doubt that you, sir, and your brilliant team fully 9 understand the importance of this process to the many 10 thousands of people whose lives have been deeply affected, either by the loss of a loved one or in so 11 12 many other ways by the twin tragedies of infection with 13 Human Immunodeficiency Virus and the Hepatitis C virus as a result of treatment with blood or blood products by 14 15 the NHS in Scotland.

16 Those lives include not just the patients and their 17 families but also the many dedicated professionals 18 responsible for all aspects of the blood transfusion 19 service and for the treatment of patients throughout the 20 period. This last aspect is perhaps more apparent after 21 the public hearings than it was before.

It is axiomatic that twin disasters such as HIV and the Hepatitis C, as traumatic and far reaching as they are, should be the subject of some form of official public Inquiry. It is a pity that, because of the

surprising and disappointing failure by Government until
 now to appreciate the need for a detailed official
 public examination of the facts, evidence has been lost,
 witnesses have died and memories have faded.

5 On the other hand, it is still possible to 6 reconstruct a great deal from the testimonies and 7 documents that are available, and it is clear from the 8 material that some of the key players appreciated the 9 likelihood that a retrospective would one day be 10 necessary and so recorded and made available much 11 information with that in mind.

12 The Inquiry has investigated a number of topics in 13 the course of this phase and the final report will 14 hopefully contain many of the answers sought.

Some of the answers are relatively straightforward but nonetheless need to be set out with clarity. Some answers are more complicated, although not necessarily controversial, and it is to be hoped that it will be possible to explain these matters in a way that is accessible and comprehensible to the layman.

21 An attempt has to be made to answer more 22 controversial issues. It is inevitable that at the end 23 of the process, with the best will in the world, it may 24 not be possible to provide a complete answer to all of 25 the questions. But even the exercise of narrating that

state of affairs in relation to such questions has
 a value for those involved.

I have referred to the disasters of HIV and Hepatitis C as "twins", but they are not identical twins. One of the important tasks of the Inquiry is to understand, explain and highlight the differences as well as the similarities of the disasters, and the impact each had upon the other.

9 I would like to say something now about the nature 10 of the process, and what I have to say applies to the 11 whole of the Inquiry as opposed simply just to the 12 public hearing phase with which we have been involved.

13 In some ways it's easier to characterise the nature 14 of the Inquiry by saying what it is not. It is most 15 certainly not a civil litigation. There is no place for 16 legal concepts such as the standard of care, fault and 17 causation, or even for concepts borrowed from 18 administrative law.

19 The search for answers is not about pointing the 20 finger or attributing blame, although it will no doubt 21 be necessary to criticise certain decisions as mistaken, 22 incorrect or wrong, just as other decisions were 23 fortunate or sensible or wise.

24 Explaining what occurred in clear terms and25 acknowledging decisions good and bad is important. Our

understanding is that the Inquiry's intention is to
 examine decision-making at a strategic level rather than
 scrutinising decisions of particular individuals.

If that is so, one wonders: why all this 4 defensiveness? Why is it so hard for institutions like 5 the NHS and Government departments responsible for its 6 7 administration to admit publicly mistakes and 8 misjudgments? If the submissions on behalf of the NHS 9 and Scottish Government are to be taken at face value, 10 then no mistakes were made, no regret is expressed and communication with patients was as good as it possibly 11 12 could have been.

Such defensiveness is not helpful but it is also not necessary, given the nature of the project in which we are all engaged. A fearless recognition, where appropriate, that mistakes were made would be so much more constructive and beneficial for everyone.

More than anything, this process will have a value if it can repair some of the mistrust that was created by unrealistic expectations, a lack of transparency, a failure to communicate effectively and an unwillingness to be upfront in relation to the threat posed by the risks that were present.

24 One of the those important themes to emerge is the 25 difficulty of effective communication, not just between

1 doctors and nurses on the one hand and patients on the 2 other, but also between organs of central government and 3 the transfusion service, and within the transfusion 4 service itself.

5 I will return to the theme of communication in a few 6 moments.

7 I would like now to make some remarks about the need8 for the process to recognise the harm.

9 One of the most important functions of the Inquiry 10 is to record the harm suffered by individuals and their families as a result of the twin disasters. That is not 11 12 simply a case of recording the numbers of lives lost or 13 the numbers infected, difficult though these two things 14 are; it is also necessary to narrate the far-reaching 15 consequences of infection and treatment on individuals 16 and their families.

Chapter 4 of the preliminary report records the
experiences of patients and their families. It seems to
be entirely accurate.

In addition, during the evidential hearings we heard
exceptionally powerful testimonies, from Amy, Christine,
David, Elaine, Frances and Mark in relation in
particular to HIV, and Alex, Anne, Bridie, Colin,
Gordon, Laura and Stephen in relation in particular to
Hepatitis C.

1 The Inquiry also has important evidence from experts 2 on the effects of HIV and Hepatitis C, the effects of 3 treatment and the consequences and effects of 4 co-infection. It also has a considerable number of 5 witness statements from patients and relatives who, 6 although not called to give evidence, have taken the 7 opportunity to tell their stories.

8 The Inquiry also has material from Jean Tamburrini, 9 Roseleen Kennedy, as well as the statements from 10 Mrs Black and Mrs Laing in relation to the individual 11 deaths.

12 Further work is ongoing in relation to giving 13 reliable figures for the numbers infected and the 14 numbers of deaths as a result of treatment by the NHS in 15 Scotland.

16 The Inquiry also has significant material in 17 relation to the financial consequences of infection and 18 co-infection. There is, therefore, every reason to be 19 confident that the final report will carefully document 20 all of the effects, so that a permanent, accurate record 21 of the adverse consequences of the disasters suffered 22 and continuing to be suffered by patients and their 23 families will be available.

I would now like to make some remarks about certain themes that emerge from our submissions.

1 Our detailed written submissions expand upon some of 2 the more contentious areas covered by the Inquiry. Some 3 of the themes that emerge from those submissions should 4 be highlighted. There are five of these in relation to 5 HIV.

6 One, we say that the "business as usual" decision by 7 senior haemophilia clinicians, and seen in the letter 8 from Professor Bloom of May 1983, was wrong in the light 9 of the available information at that time. Patients 10 should have been offered different treatment from that 11 point on.

12 Two, we say that there was complacency, at least for 13 a time, that HIV was an American problem for which 14 recipients of blood and blood products would be 15 protected due to the voluntary donor system.

16 Three, we say that the Government, the Department of 17 Health and Social Security, the Scottish Home and Health 18 Department and the Scottish National Blood Transfusion 19 Service and clinicians all publicly understated the risk 20 posed to the blood supply from AIDS long after it must 21 have been known that there was a significant danger.

It was represented in the press that the public had nothing to worry about, even after haemophiliacs in Edinburgh had tested positive for the presence of the virus.

1 Four, there was a failure to share information 2 across disciplines. In 1983 the transfusionists were very concerned about the prospect that HIV had entered 3 the donor population but they do not appear to have 4 shared those concerns with the haematologists. The 5 attitude of the latter might be summed up by the 6 7 statement of one of them during the evidence, which was:

"We were not in the infectious diseases business." 9 One lesson that this Inquiry should be able to drive 10 home to anyone interested is that treating patients with blood or blood products is very much being in the 11 12 infectious disease business.

8

13 Five, time and time again blood samples were 14 analysed without express knowledge or consent of 15 patients providing those samples. This was a widespread 16 practice that occurred in the West of Scotland as well 17 as Edinburgh.

18 It was wrong, it was compounded by a failure to 19 obtain express permission from patients to publish the 20 results of continuing studies in relation to those 21 samples, even yet permission in respect of work 22 conducted in relation to samples obtained many years ago 23 has not been sought. This practice has made 24 a significant contribution to the anger and mistrust on 25 the part of patients in relation to those responsible

1

for their long-term treatment.

2 In relation to Hepatitis C, I have seven points. 3 First, the most important point is the lack of appreciation on the ground of the threat from non-A 4 non-B Hepatitis and the lack of action in response to 5 the threat. No doubt the insidiousness of the disease 6 7 meant that the danger was not fully appreciated but it was known from the mid-1970s that there were 8 9 unidentified hepatitis viruses in the donor pool, and it 10 was known from the early to mid-1980s that the virus known as "non-A non-B Hepatitis" would be likely to 11 12 result in serious adverse consequences for patients.

13 It was also known from the early 1980s that blood 14 products made from large donor pools would almost 15 certainly transmit the virus.

16 Secondly, an unnecessary risk was taken by 17 continuing to collect blood from prisons until early 18 1984. The decision to leave it to regional transfusion 19 directors to decide whether and when to stop collecting 20 blood was wrong. In the light of the available 21 evidence, a direction to stop collecting blood from 22 prisons should have been taken nationally by the end of 23 the 1970s at the latest. Such a decision would not have 24 adversely affected the blood supply.

25 Three. Surrogate testing for non-A non-B Hepatitis,

as Hepatitis C was known, should have been introduced
 when the Scottish National Blood Transfusion Service
 made its recommendation to the Scottish Home and Health
 Department in March 1987.

5 The Scottish Home and Health Department 6 underestimated the significant public health risk posed 7 by non-A non-B Hepatitis and did not react urgently and 8 adequately to the threat posed.

9 Four. It took far too long to introduce screening 10 tests for Hepatitis C between the isolation of the virus 11 in 1988 and their introduction in September 1991.

12 Scotland lagged considerably behind other countries 13 in this regard. Japan, Australia, France, Finland, the United States, Germany, Canada, Belgium, Switzerland 14 15 Italy, Norway, Sweden, Netherlands, Denmark, Malta and 16 Cyprus, among others, all beat us to it. In the 17 dithering that went on between 1989 and 1991, the SHHD and SNBTS lost sight of the interests of patients. 18 As 19 was put by Dr McClelland in his evidence:

20 "Nobody appeared to consider the question: what
21 about the patients?"

Five. There was a failure to reduce to a minimum the risk to virgin and minimally-treated haemophiliac patients in the period between January 1986 and April 1987, when Scottish Factor VIII was not

sufficiently heat-treated to inactivate the virus
 causing non-A non-B Hepatitis.

This was at a time when it was known that treatment with SNBTS Factor VIII would certainly infect a patient with that virus and that it was likely that such infection could result in cirrhosis of the liver, hepatic cancer and death.

8 Six. Look-back -- that is the tracing of the 9 recipients of infected blood -- should have started when 10 screening for Hepatitis C was introduced in Scotland in 11 1991. As Dr Gillon of the SNBTS maintained at the time 12 and maintained in his evidence:

13 "It was the ethical thing to do."

He was right then and he was right when he gave his
evidence.

16 Seven. One of the most damaging aspects for 17 patients has been the extent to which sufferers of 18 Hepatitis C have been stigmatised as abusers of alcohol 19 because of a failure by health professionals to 20 appreciate the damage to the liver caused by the virus. 21 This is an experience repeated time and time again in 22 the case studies. The problem stems from a lack of 23 appreciation of the long-term liver damage caused by the 24 virus.

I do want to say something in relation to

25

1 communication which relates to both HIV and Hepatitis C. 2 The evidence of patients is clear that, one, they were not given sufficient information about the risks 3 associated with treatment by blood and blood products; 4 two, patients were not told that they were being tested. 5 This occurred in relation to Hepatitis C, even after it 6 7 must have been obvious that testing for HIV without 8 consent was unacceptable from the point of view of 9 patients.

10 Three. There were significant and unacceptable 11 delays between a positive test for infection and that 12 information being relayed to patients.

Four. Patients were given incomplete, inadequate and misleading information about the consequences of being infected with the virus.

Failure in communication occurred not just between doctor and patient, but also within medical disciplines; between the top and the bottom and across medical disciplines, between transfusionists and haematologists and haematologists and virologists.

21 I want to make some concluding remarks.

It would be wrong for anyone to think that the National Health Service can always offer relief from the heartache and the thousand natural shocks that flesh is heir to. Indeed, it is right that tribute should be

paid to all of the hard-working medical staff, all the hard-working fractionating staff, who provided treatment and products to patients during the time we have been examining.

5 Although a critical eye is cast in relation to 6 certain decisions, it is right to record genuine and 7 heartfelt gratitude for the excellent treatment received 8 by patients much of the time.

9 But three key words are worth emphasising, and I do 10 so in reverse order: service, health and national.

11 It is a service for the benefit of patients and 12 their families. Their welfare should always be at the 13 centre of all decision-making. The patient should be in 14 control, not the health service professional. The 15 essence of this is the autonomy of the patient. 16 Decisions in relation to treatment and care are for the 17 patient and, where appropriate, their carer.

Health. Decisions should always be taken in the best interests of promoting the health of patients. Some of the delays that occurred in Scotland were because other considerations overrode the interests of patient health, and we make specific reference to these instances in our submissions.

National. There are two points here. The first isthe obvious regional variation in practices and

standards during the reference period. There was a lack
 of national direction and decision-making throughout.
 Standards of service varied throughout the country.

Dr Cachia's testimony that he was a bit horrified by what he found when he arrived in Dundee in 1992, to find that Hepatitis C testing was being carried out on patients' stored samples without consent being obtained, is one example of many regional variations in standards.

9 The second point is the failure of the 10 Scottish Health Service, legally and administratively autonomous as it was, to make decisions for itself. 11 12 There were many situations, such as the delays in the 13 introduction of donor screening and surrogate testing and look-back of HCV to name but three, where the 14 15 decision not to implement these things was taken so as to avoid stepping out of line with the rest of the 16 17 United Kingdom.

This is not a political point but where the NHS in Scotland has the autonomy, and we most certainly do not accept that it did not have the autonomy at the relevant time. If it's right to do something or follow a particular course of action in the interests of patient safety, then it should get on and do it and not wait for a lead from anywhere else.

25 Sir, you have heard many harrowing stories from

1 patients who suffered the terrible consequences of HIV 2 or Hepatitis C, and in the case of haemophiliacs frequently both. You heard of mothers, who, as carriers 3 of haemophilia, had to come to terms not only with 4 passing on the condition to their son, but then 5 6 administering what they thought was life-transforming 7 medication only to realise that their child had been 8 infected with HIV, and then they had to stand by and 9 watch as the child fell ill and died.

10 The twin disasters have really happened to real 11 people. They needed and need support. Many of them 12 have suffered significant deteriorations in their 13 conditions since the start of this process. They needed 14 and need understanding, they needed and need 15 explanations, and they needed and need mistakes to be 16 acknowledged and improvement to be made.

I am confident that the Inquiry will do what it can in fulfilling its terms of reference to meet those needs.

20 Thank you.

22

21 THE CHAIRMAN: Mr Anderson?

Submissions by MR ANDERSON

23 MR ANDERSON: Thank you, sir.

Today's final hearing has been long awaited. It is almost three years to the day since the preliminary

hearing in this Inquiry was held at Edinburgh
 International Conference Centre on 31 March 2009.

Since then, the first phase of the Inquiry has 3 resulted in the publication of the preliminary report, a 4 notable achievement in itself and the result of an 5 6 in-depth analysis by you, sir, as chairman of this 7 Inquiry and the Inquiry team of the great mass of 8 documentation recovered under the Inquiry's terms of 9 reference from numerous sources, including both the SNBTS and the Scottish health boards. 10

11 The second phase, the oral hearing, started 12 approximately one year ago on 8 March 2011 and concluded 13 on 20 January this year.

It has been apparent throughout this period to all 14 15 those involved that the Inquiry team has been extremely diligent in its research into what are matters of 16 17 considerable scientific and medical complexity. In the 18 first place, therefore, I should wish to express my 19 appreciation on behalf of NHS Scotland of the Inquiry 20 team's dedication and also the very competent manner in 21 which it has carried out this challenging task.

It is also appropriate to record appreciation to both those bereaved relatives who gave evidence in relation to the specific deaths and to the anonymised witnesses who gave evidence regarding the effects of

living with either HIV or Hepatitis C, or both viruses.
 It requires little imagination to appreciate how
 difficult it must have been for those individuals to
 give evidence before this Inquiry about such painful
 events and with such admirable restraint and dignity.

Next, it is appropriate, I think, to record
appreciation of other witnesses who gave oral evidence
to the Inquiry, and particularly those who attended
despite their advanced age.

10 Some witnesses gave evidence on more than half 11 a dozen occasions. Two witnesses, I think, each making 12 as many as ten appearances. Many were in their 70s, 13 some in their 80s, and much of the time were having to 14 recollect events that took place 30 or so years ago.

I'm sure that everyone involved in the Inquiry will agree that all of the many witnesses from whom the Inquiry took evidence displayed a real commitment to assist the Inquiry in its investigations. Of course, many were giving evidence about what was effectively their life's work.

21 Notwithstanding the difficulties presented by the 22 passage of time, the fact that some key participants 23 have died and the wide-ranging nature of this Inquiry, 24 there seems little doubt that the thoroughness with 25 which this Inquiry has been undertaken should provide

all those with an interest in the subject with

1

2

a definitive statement in the form of the final report.

3 None of the previous Inquiries held in this and 4 other countries have gone into such depth of detail 5 about both treatment and scientific issues as has the 6 present Inquiry.

For this reason it is hoped that this Inquiry will
provide the foundation for a new, more balanced and
evidence-based understanding of events in the past.

10 In this regard it has, in recent weeks, been 11 disappointing to see that even after the conclusion of 12 hearing almost a year of oral evidence, there are still 13 those who persist in describing the subject matter of 14 this Inquiry, in a media context, as "a scandal".

15 No doubt some will say, and indeed has just been said, that certain things might have been done 16 17 differently or that different decisions might have been 18 taken. That may or may not be correct. But of this 19 there should be no doubt: there is no justification for 20 the description of events as "a scandal". There is and 21 was no scandal. That word always carrying with it the 22 connotation of wrongdoing of one sort or another.

It may be appropriate now to comment briefly on the synopsis presented just now by my learned friend Mr Di Rollo of the criticisms contained within their

very full written submissions. I would propose to deal
 with only those that might be regarded as the more
 controversial.

4 Starting in relation to HIV, there is repeated 5 criticism made in relation to testing without consent. 6 This is a criticism that is now made but significantly 7 was never apparently made at the time. This is, in my 8 submission, perhaps the most obvious case of looking at 9 events of the early 1980s through 2012 spectacles.

10 Careful analysis of the evidence from independent expert witnesses will, I suggest, confirm that there 11 12 should be no criticism of clinicians who tested stored 13 samples in what was considered to be their patients' 14 best interests, and it is, in my submission, not 15 justified to characterise that practice as "wrong". It may be wrong by present day standards but it was not 16 17 wrong by the standards of the early 1980s.

18 In relation to Hepatitis C, dealing with surrogate 19 testing, it's important to appreciate that there was 20 never at any time any consensus on the usefulness of 21 surrogate testing. To suggest now that just because it 22 was not introduced, it should have been introduced is 23 simply not accepted. But, sir, you have the full 24 submissions in relation to that, both of course on behalf of the NHS and the submissions on behalf of the 25

1 Scottish Government.

2 In relation to donor screening, again, the criticism is not accepted. Despite what my learned friend has 3 just suggested, the world was different then. This was, 4 of course, a pre-devolution era. Health is now 5 a devolved matter. Then Scotland had no autonomy. The 6 7 introduction of donor screening was a large national 8 exercise in which the Department of Health naturally 9 took the lead. Again, it's perhaps sufficient to refer 10 to the written submissions of the NHS, and indeed again of the Scottish Government, on this point. 11

12 We can perhaps now look back from 2012 and see, as 13 counsel to the Inquiry very aptly put it, that a number 14 of small delays may have added up to a bigger one. But 15 the suggestion that SNBTS had the power to cause a departure from the well recognised status quo, in my 16 17 submission ignores the realities of the situation and 18 the suggestion within the written submissions that this 19 was an abrogation of responsibility by SNBTS is to 20 misunderstand the role of the SNBTS.

Finally, in relation to the criticism, caution, I think, requires to be exercised in relation to the difficult topic of communications between doctors and patients.

The difficulty, I would suggest, is that the

25

criticisms that my learned friend Mr Di Rollo makes are predicated upon simply accepting everything that the patients say is right, and I would simply suggest to you, sir, that facts are not as simple as that.

It has also been noted that the written submissions 5 made to the Inquiry on behalf of the patient interest 6 7 core participants make repeated criticisms based on 8 suggested alternative strategies or treatment which were 9 never explored with any witnesses in evidence. These 10 submissions and what it is said should have been done represent an exercise in hindsight which frequently 11 12 ignores the totality of the evidence.

13 The fact is that there are risks associated with all medical procedures and the transfusion of blood and use 14 15 of blood products are no different. Despite the 16 considerable number of blood transfusions carried out in 17 Scotland every year, the possibility of transmission of 18 an unidentified infective agent, which is naturally 19 present in the human population, is rare; nevertheless, 20 this rare risk is inherent in treatment with blood and 21 blood products.

Also, in the context of media coverage, it should be stressed that the use of the term "contaminated blood" is a misnomer insofar as that term implies that something has been added to blood.

Both HIV and Hepatitis C are naturally occurring blood-borne viruses and the vast majority of patients to whom these viruses were transmitted were infected before the viruses had been discovered by medical science, before medical science had devised tests to detect these viruses and before it was possible to screen blood donors.

8 Across the world, making blood and blood products 9 safe from these viruses represented significant 10 milestones in the advance of transfusion science and 11 transfusion medicine.

12 In this global sense, Scotland not only played its 13 part in these advances but was at the forefront 14 including being, firstly, one of the first countries in 15 the world to provide Factor VIII concentrate from its 16 own donor population in sufficient quantities to treat 17 its own patient population; an achievement described by 18 the Inquiry's expert, Professor van Aken from the 19 Netherlands, as "remarkable" and "a real big success". 20 Secondly, Scotland was the first country to supply sufficient heat-treated Factor VIII concentrate safe 21 22 from HIV.

23 Thirdly, it was the first country to supply24 sufficient heat-treated Factor VIII concentrate safe25 from Hepatitis C long before the major commercial

1 companies did.

2 Fourthly, it made Factor VIII and Factor IX 3 concentrates safe from Hepatitis C, even before the 4 virus had been isolated; and finally, it was one of the 5 first countries to conduct a Hepatitis C look-back 6 exercise.

7 Although the achievement of making blood and blood 8 products safe from the transmission of HIV and 9 Hepatitis C represented significant medical advances, 10 nevertheless it is a highly regrettable but unavoidable fact that whenever such advances exist in medicine, 11 12 there will always be patients who are unable to benefit 13 from the development having been treated at an earlier 14 time.

15 Following on from these advances of the 1980s and early 1990s, there have been many further significant 16 17 developments in the safety of blood and blood products 18 provided to Scottish patients. To give but one example: 19 following the licensing in the UK of commercial 20 recombinant non-human factor concentrates in 1995, 21 Scotland achieved their routine use several years before 22 the rest of the UK.

23 Developments such as these have not been able to be
24 explored in evidence having been considered by the
25 Inquiry team to fall outwith the historical scope of

this Inquiry as set out in its terms of reference.

1

2 It should not be forgotten that the development of 3 concentrates prolonged the lives of many patients with haemophilia and greatly enhanced their quality of life; 4 nor should it be forgotten how difficult a position 5 haemophilia clinicians found themselves in when faced 6 7 with the dilemma of continuing to treat their patients 8 against the background of the emergence of HIV, 9 a totally new and unprecedented fatal virus, and one 10 about which medical science was initially divided as to its origin and its mode of transmission. 11

12 Equally, haemophilia clinicians faced further 13 challenges due to the emerging knowledge throughout the 14 1980s of the consequences of non-A non-B Hepatitis, 15 later identified and described as "Hepatitis C".

In his evidence, another of the Inquiry's experts,
Professor Lever, expressed the opinion that:

18 "During the emergence of HIV there would not have
19 been an expert there at the time who could justifiably
20 have said what was going to happen with HIV, far less go
21 on to specify what clinicians must do."

As Inquiry witness Professor Forbes, formerly of Glasgow Royal Infirmary, put it, it was certainly not possible to stop the use of concentrate as bleeding would have resulted in death.

As events unfolded around HIV, it was the dedicated efforts of the haemophilia clinicians, and in particular the close monitoring of their patients, which resulted in early confirmation that HIV had entered the Scottish donor population, which resulted in a swift and effective response from the SNBTS in terms of virus inactivation.

8 Whilst in no way minimising the devastating outcome 9 for the patients who acquired HCV, Hepatitis C and/or 10 HIV, the low rate of infection in Scotland by international standards stands as testimony to both the 11 12 efforts of the SNBTS to make blood for transfusion and 13 blood products as available and safe as possible and 14 possible for clinicians to use blood and blood products 15 wisely and only where necessary.

The SNBTS has always been driven by the commitment 16 17 to save and improve lives and counter illness while 18 fully supporting its donors. It has worked tirelessly 19 throughout its history to provide sufficient, safe and 20 effective treatment for all patients who require 21 life-saving blood and blood products. The development 22 of such life-enhancing treatment has always posed 23 challenges to which the SNBTS has consistently faced up 24 as and when they arise.

25 Equally, Scottish clinicians have at all times been

driven by what they considered to be in their patients'
best interests. The evidence before this Inquiry has,
in my submission, demonstrated that they acted in good
faith to administer what they in their clinical judgment
considered to be the best available care.

6 These events had a profound and lasting effect on 7 those working within the SNBTS and on the medical and 8 nursing staff within the health boards, who dedicated 9 their professional lives to the development of safe 10 products and to the care of their patients.

11 It is a matter of the greatest regret to NHS 12 Scotland that patients were infected with the HIV and 13 Hepatitis C viruses as a result of medical treatment, 14 and every sympathy is extended to those infected and 15 perhaps, above all, to the bereaved relatives.

Finally, as previously noted, this Inquiry has dealt 16 17 with events which occurred some 30 or so years ago. This should not detract attention from the fact that 18 19 blood testing and processing systems used in Scotland 20 today provide extremely high levels of safety and that 21 NHS Scotland continues now, as before, to rely heavily 22 upon blood donations given voluntarily by the people of 23 Scotland.

In Scotland around 50,000 patients every year
receive life-saving blood transfusions. Accordingly, it

1 remains as vital now as it always has been for donors to 2 continue to support the Scottish National Health Service in caring for the people of Scotland. 3 Thank you very much, sir. 4 THE CHAIRMAN: Thank you, Mr Anderson. Mr Johnston? 5 6 Submissions by MR JOHNSTON 7 MR JOHNSTON: It was on 23 April 2008 that the Cabinet 8 Secretary for Health and Wellbeing announced to the 9 Scottish Parliament the establishment of this Inquiry. 10 The Government was conscious that the transmission of Hepatitis C and HIV through blood and blood products 11 12 was a tragedy that had blighted the lives of many people 13 in Scotland. Nothing could ever make amends to those people or their families for that but it was recognised 14 15 that they were entitled to an explanation of how 16 Hepatitis C and HIV came to be transmitted through NHS 17 treatment in Scotland. The setting up of this Inquiry reflects the policy 18 19 that informs the whole NHS in Scotland nowadays to offer 20 healthcare which is safe, effective and focused on 21 patients. 22 In the spirit of that policy, it is important to 23 provide explanations when things have gone wrong and 24 assurance that lessons will be learned for the future. Even at the outset, it was clear that the Inquiry 25

had an enormous task before it. It would have to carry
 out a detailed investigation into the circumstances in
 which Hepatitis C and HIV were transmitted through the
 blood and blood products used in NHS treatment.

5 It would have to consider whether, in light of the 6 epidemiological and scientific knowledge available at 7 the relevant times, all that could be done to protect 8 the public had been done.

9 It would have to explore the consequences of 10 transmission of these viruses for the patients affected. 11 This would involve reconstructing events going back as 12 far as 1974 with such help as witnesses could still 13 provide and by reference to voluminous quantities of 14 documentation which the government and other bodies 15 would supply to the Inquiry.

By the time of the announcement in April 2008, many key documents were already in the public domain. There had also been a number of previous inquiries and investigations into the issues. But those inquiries, valuable though they were, were carried out by Government and lacked independence.

The Government recognised that it was essential to have an investigation which had the credibility and authority of a full and transparent Scottish public Inquiry.

1 Since the Inquiry was established, it has had the 2 total support of the Scottish Government. While the 3 Government has taken part as a core participant in the 4 Inquiry, it has nonetheless respected the need for the 5 Inquiry to be absolutely independent.

At this stage, after publication of the preliminary report in 2010 and after the completion of 88 days of oral hearings in 2011 and 2012, it is to the chairman of the Inquiry and the whole Inquiry team that particular thanks are due.

11 These thanks are not limited to those who are 12 visible in the hearings, but extend to all those who 13 have provided essential support behind the scenes. The 14 Government is extremely grateful to the chairman and the 15 Inquiry team as a whole for the extraordinary amount of 16 work and commitment that they have devoted to 17 identifying, investigating and analysing the issues.

18 The magnitude of the work facing the Inquiry has 19 already been mentioned. In that context, the Government 20 would also wish to express its appreciation of the fact 21 that the Inquiry has succeeded in investigating so many 22 complex issues so thoroughly.

It also pays tribute to the considerable efforts that the Inquiry has made to ensure the openness and transparency of its proceedings, not least by making it

possible to follow them from day to day on the Inquiry
 website.

Equally, it recognises the great efforts that the Inquiry has made to respect the privacy of the courageous individuals who came forward to give first hand accounts of their experiences of HIV and HCV.

As the Cabinet Secretary has previously
acknowledged, nobody can undo the pain and suffering of
the people who were affected by HIV or Hepatitis C as
a result of treatment with blood and blood products; but
they can be offered an explanation and they can be
provided with assurances that lessons can be learned.

13 The Government expresses the hope that the Inquiry, 14 when it reaches its final conclusion, will provide that 15 explanation and those assurances. It therefore looks 16 forward to receiving the final report and

17 recommendations in due course.

18 Thank you.

19 THE CHAIRMAN: Ms Dunlop?

20 Submissions by MS DUNLOP

21 MS DUNLOP: Thank you, sir.

22 There are two principal areas I wish to address in 23 my remarks.

Firstly, I should explain that the team of Inquirycounsel has itself produced a list of issues relating to

each numbered topic. This is at [PEN0190843]. These
 were the matters that seemed to us as Inquiry counsel to
 be the main points arising under each topic. We drafted
 these lists in the hope that they would be of assistance
 in the preparation of the final report.

6 We have not, however, proposed how those questions 7 should be answered because they relate in many instances 8 to issues which are controversial, and it appeared to us 9 to conflict with our position of neutrality to advance 10 submissions as to how controversial issues should be 11 resolved.

12 At this point, I should refer to the matter of 13 statistics. There is work ongoing, in particular in 14 relation to the attempt to establish the number of 15 people who acquired Hepatitis C as a result of blood transfusion. We will continue to keep all core 16 17 participants informed of the progress of that work, which I hope will be concluded in reasonably early 18 19 course.

In relation to statistics, I should also take this opportunity to correct an impression given by the transcript at the end of the day on 18 January 2012. In fact at that point Professor Goldberg of Health Protection Scotland had provided the Inquiry with further information on statistics, as he undertook to do

in his evidence last March, and had carried out
 extensive work in doing so.

The second area I want to address is in relation to the phase of the Inquiry which began when we took occupation of these premises, I think at the end of 2010. That phase, the hearings phase, followed a period of preparation during which the Inquiry team published the preliminary report. It would not be controversial to describe this hearings phase as "phase 2".

10 A great deal of effort on the part of many people in 11 the Inquiry team has contributed to phase 2, and on 12 behalf of Inquiry counsel I would like to thank those 13 individuals.

14 Firstly, I must acknowledge, sir, on behalf of us 15 all, your own industry in devoting so much time and 16 effort to staying abreast of the evidence throughout.

17 In addition, your flexible approach to matters of 18 timing and of procedure has greatly assisted in the 19 running of the hearings. Professor James, the medical 20 assessor, is not here today, but, of course, his 21 willingness to help us all with the many incidental 22 medical questions as they arose has been much 23 appreciated.

To all the lawyers who have represented all the core participants, we express our sincere gratitude. We did

not always agree but the unfailing courtesy and good
 humour shown by everyone in the front rows has made the
 experience very much better than it could have been.

4 Our own solicitors, Douglas Tullis and Louyse 5 McConnell-Trevillion, have kept us on the straight and 6 narrow, we hope, and dealt with the reams of 7 correspondence and probably a million emails. We thank 8 you from the bottom of our inboxes for relieving us of 9 that burden.

10 Our Inquiry secretary, Maria McCann, has helped at 11 every turn, as have Sarah and Meg, and, normally back at 12 Drumsheugh Gardens, Kate Miguda and Charles Rogers. The 13 can-do attitudes displayed by all of you have been 14 remarkable.

Margaret Fraser, as well as looking after witnesses throughout, has supplied us with multi-coloured witness availability spreadsheets, which were indispensable. I should of course acknowledge that the other half of that, the witnesses making themselves available to us, has also been something that we could not have done without.

22 We have been well catered for literally, too; Scott 23 and Raymond, our security guards, have trudged out in 24 all weathers, every day, for our lunches, as well as 25 discharging their duties at the front desk and looking

after my bike every time I forgot my lock.

1

2 Our documents team have remained cool, calm and 3 efficient at all times, despite, in their own words, 4 having to "paddle madly below the surface" from time to 5 time.

External contractors have also provided high quality
assistance throughout, insofar as the task of assembling
and displaying our many documents is concerned.

9 Neil, Ollie and Keith, court book stands as 10 a monument to you all, to say nothing of the behemoth that is Signature, lying beneath. Our stenographers, 11 12 who have provided the transcripts, Stuart and Catherine, 13 have served us without fail and have produced the best 14 transcripts I have ever seen. I do hope that even 15 a small amount of the arcane vocabulary will be useful to you some day, somewhere. 16

17 Focusing more closely on the presentation of 18 evidence brings me to the topics teams, Gregor Mair, 19 Lindsey Robertson, Janet Marsh, Angus Evans, 20 Gemma Lovell and Yasmin Shepherd, the lawyers who have 21 assisted us. We simply could not have managed without 22 you. Your knowledge of your own tranches of time within 23 the Inquiry period from the documents exercise enabled 24 you to move seamlessly to the in-gathering of statements 25 and other material for the hearings. The preparation of

inventories and the assembly of folders for us all and
 your thoroughly dependable input on a range of tasks has
 massively assisted throughout phase 2.

Finally, I have for the first time in my career, had
three junior counsel. I have never had it so good.
Jane Patrick, Euan Mackenzie and Nick Gardiner have
worked tirelessly and offered ceaseless support. All
four of us have learned much during this exercise and it
has been a privilege for us all to serve as Inquiry
counsel.

11 Closing Statement from THE CHAIRMAN 12 THE CHAIRMAN: Ladies and gentlemen, you have heard quite 13 diffusive thanks offered to many people, often with 14 names that will mean absolutely nothing to you. I will 15 have my opportunity to express my thanks to all those 16 who have contributed to the work of the Inquiry in due 17 course and I won't repeat that now.

18 It will be clear from what you have heard this 19 morning that there is a great deal now to do to bring 20 the Inquiry to a conclusion. There has been 21 a staggering amount of evidence. All of it will have to 22 be looked at, all of it will have to be analysed so far 23 as it bears on the critical issues that still have to be 24 resolved.

There are some issues of basic fact, there are some

25

issues of inference from fact and some impressions and it will not be possible to accept all the evidence as credible and reliable, although we have to say in this case reliability is likely to be the issue rather than credibility, which often causes trouble in litigation, which is not, of course, this case.

7 These investigations of the evidence, discussions 8 and analysis, they will take time. I can't promise to 9 produce a final report in a period of time that is 10 shorter than necessary to ensure that the end product 11 reflects the value of the input material, but it will be 12 done as soon as reasonably practicable.

13 While I don't want to take time thanking all of 14 those who have contributed to the exercise, I do want to 15 express my deep gratitude to all of those who have 16 attended and given evidence at this Inquiry. Those who 17 have never given evidence hardly ever understand the 18 demands that appearing before any sort of tribunal make 19 on the individuals involved. Whether they are professionals, whether they are individuals directly and 20 21 personally affected by the events, giving evidence is 22 not easy for them.

It is particularly difficult, of course, for those who come to give personal accounts of experiences that have affected their lives very deeply, and that applies

principally to patients. It also applies, as has become clear, to some of the clinicians who have been directly involved in patient care.

4 I am very, very grateful that people have been5 willing to come forward.

I don't want anyone to underestimate the extent to 6 7 which this Inquiry has been assisted, particularly by 8 patients and by families of patients, in coming to give 9 statements on which we can develop a picture of the 10 impact of these diseases on people's lives. So I thank all of you really very deeply for the work that you have 11 12 done, the preparations that you have made and for the 13 willingness that you have shown, where you have been 14 invited to do so, to come and give oral evidence to the 15 Inquiry.

We are now at the end of the gathering of evidence, 16 17 with one exception. Ms Dunlop has referred to it, the 18 need to tighten up and reach a final conclusion on the 19 statistical material available to the Inquiry, to assess 20 the extent to which there are still people in the 21 community in Scotland with Hepatitis C that is related 22 to their treatment, so that the government can be 23 informed of the extent of the continuing problem, a very 24 important aspect of this Inquiry's work and one in respect of which I am personally less than happy to 25

1 reach a final conclusion without being satisfied that we 2 have at least tried to identify the stones and turned them over, even if we don't manage to find all that 3 4 lurks underneath. 5 With that exception, statement taking is at an end 6 and evidence-gathering is completed. It now is for 7 Professor James, for myself and for the Inquiry team to 8 settle down and reach a concluded view on the very many 9 issues that have been left for us to determine in the 10 light of all that has been said and done. Thank you all very much for your contributions. 11 12 (11.11 am) 13 (The hearing adjourned) 14 15 INDEX 16 17 Submissions by MR DI ROLLO1 18 Submissions by MR ANDERSON4 19 Submissions by MR JOHNSTON6 20 Submissions by MR DI ROLLO7 Submissions by MR ANDERSON22 21 22 23 24 Closing Statement from THE CHAIRMAN42 25