Witness Name: Dr Peter Jones
Statement No.: WITN0841005
Exhibits: WITN0841006-WITN0841035
Dated: 17 September 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF
DR PETER JONES

I, Dr Peter Jones, provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14 January 2020 and will say as follows: -

Section 1: Introduction

1. *Please set out your name, address, date of birth and professional qualifications.*

   Mr Peter Mercer Jones, (Address known to the Inquiry), Dob GRO-C 1937. MBBS, MD, FRCP, FRCPCH, DCH

2. *Please set out your employment history, including the various roles and responsibilities that you have held throughout your career, as well as the dates.*

   Please refer to my CV at Exhibit WITN0841006 and my Personal Record at Exhibit WITN0841007.

   I was appointed to the post of consultant paediatrician in 1970/71 and worked thereafter at the Royal Victoria Infirmary, Newcastle upon Tyne. Initially my role included general child health, but latterly became increasingly concerned with the management of haemophilia and related disorders in the Northern Region of the NHS. My Personal Record

(WITN0841005), which is also in the Inquiry files, details my progress in this regard. I retired from the NHS in 2000 but continued to work for the charity World Federation of Hemophilia as an elected member of the Executive with responsibilities for communications and fundraising. Throughout my working life the management of haemophilia both in the UK and internationally, has been of central interest and this is detailed in my Personal Record and is relevant to the Inquiry Terms of Reference.

3. *Please confirm whether you have provided evidence or have been involved in any other inquiries, investigations, criminal or civil litigation in relation to the human immunodeficiency virus ("HIV") and/or hepatitis B virus ("HBV") and/or hepatitis C virus ("HCV") infections and/or variant Creutzfeldt-Jakob disease ("vCJD") in blood and/or blood products. Please provide details of your involvement and copies of any statements or reports that you provided, including a copy of your statement(s) to the Lindsay Tribunal and, if you have it, a transcript of your oral evidence to the Lindsay Tribunal. (Please note that there is no need for you to supply the Inquiry with a further copy of your Draft Personal Record for the HIV Haemophilia litigation).*

   General Medical Council, Lindsay Inquiry Republic of Ireland, Canada (RCMP), Australia Supreme Court (for which the at Exhibit WITN0841008 entitled "An Illustrated Guide to the Pathology and Clinical Features of Haemophilia" was produced in order to explain the fundamentals of haemophilia and its treatment. I believe it has relevance to the Inquiry and, in particular, to explain the compelling need for adequate treatment as and when factor concentrates became available).

Section 2: Decisions and actions of the Newcastle Haemophilia Centre at the Royal Victoria Infirmary

4. *Please describe the roles, functions and responsibilities of the Newcastle Haemophilia Centre ("the· Centre") during the time that you worked there.*

   Please see enclosed document prepared for the opening of the rebuilt Haemophilia Centre 22nd May 1980 (Exhibits WITN0841009 and WITN0841010).

5. *How and when was the Northern Regional Haemophilia Service established and what were its roles, functions and responsibilities?*

Covered in 4.

6. *Please describe your role and responsibilities as consultant paediatrician at, and as the director of, the Newcastle Haemophilia Centre.*

This is covered in 4. Also see Exhibit WITN0841011 comprising the papers presented to the World Federation of Haemophilia 3rd European Regional congress, London, April 1976. This is the Congress at which David Owen made his announcement about Government funding for factor VIII production in the UK. See also Exhibit WITN0841012.

7. *Approximately how many patients with bleeding disorders were under the care of the Centre when you became director and over the years that followed? (If you are able to give exact rather than approximate figures, please do so).*

It is not possible to give accurate figures because the Newcastle Centre gradually became aligned with other Centres within the North Region and became responsible for their patients, specifically for the provision of home therapy, follow-up and major surgery.

8. *What decisions and actions were taken, and what policies were formulated, by you and by the Centre, regarding the importation, manufacture and use of blood products (in particular factor concentrates) during the time that you were director?*

All products used by the Centre had to be licensed within the UK. The only exception was the prescription of FEIBA which was on an individual named patient basis for the management of inhibitors.

9. *What responsibility did the Centre, and you as its director, have for the selection and purchase of blood products, and what decisions were taken by you or the Centre as to which products to use? In addressing this issue, please answer the following questions:*

9(a) *How, and on what basis, were decisions made about the selection and purchase of blood products?*

Decisions on the selection and purchase of blood products were made annually at a meeting which was attended by the Director or Co-Director, a member of the nursing staff, a member of the Pharmacy and a patient representative selected by the local branch of the local Haemophilia Society.

9(b) *What were the reasons or considerations that led to the choice of one product over another?*

Choice depended on 1) safety, 2) efficacy, 3) availability, 4) price

9(c) *What role did commercial and/or financial considerations play?*

As above.

10. *What was the relationship between the Centre/you and the pharmaceutical companies manufacturing/supplying blood products? What influence did that relationship have on the Centre's and your decisions and actions?*

There was no formal relationship and no influence allowed. All transactions were transparent.

11. *If the responsibility for the selection and purchase of blood products lay with an organisation other than the Centre, please specify which organisation and provide as much information as you can about its decision-making.*

As above. All products were purchased through the Hospital Pharmacy

12. *How did you decide which products to use for particular patients?*

As above. Throughout the year all patient· being treated were followed up. Only patients with inhibitors to factor VIII received different treatment.

13. *What alternative treatments to factor concentrates were available for people with bleeding disorders?*

Initially fresh frozen plasma, then cryoprecipitate, then concentrates, then cryoprecipitate for children.

14. *What were, in your view, the advantages and disadvantages of those alternative treatments? What use did you make of them? Do you accept that they should have been used in preference to factor concentrates so as to reduce the risk of infection? If not, why?*

The advantages of factor concentrates (as alternatives to fresh frozen plasma and cryoprecipitate) were:

- known dosage;
- smaller volume;
- ease of preparation;
- ease of injection by syringe;
- fewer immediate side effects;
- ease of storage;
- ease of carriage and handling;
- longer shelf life.

15. *What was your/the Centre's policy and approach as regards the use of cryoprecipitate for the treatment of patients with bleeding disorders? How did that policy and approach change over time?*

Cryoprecipitate was the treatment of choice for factor VIII deficient patients until 1973, when sufficient factor VI11 concentrate became available.

16. *What was your/the Centre's policy and approach in relation to home treatment and to prophylactic treatment?*

The introduction of concentrates allowed the development of home therapy and eventually prophylactic treatment. The Centre's policy was to encourage both, but initially there was some concern that prophylaxis would lead to prescription of more concentrate than was available. See Exhibit WITN0841013.

17. *What was your/the Centre's policy and approach in relation to the use of factor concentrates for children?*

Until the advent of HIV infection, children were started on concentrates rather than cryoprecipitate in order to allow unfettered schooling. With the advent of HIV Infection, cryoprecipitate was again prescribed in preference to concentrates.

18. *You are reported (see the enclosed article in The Irish Times dated 13th July 2001) as having stated that in Newcastle your policy was to treat children aged under six with cryoprecipitate rather than factor concentrates. Please confirm. whether this was your policy; set out the reasons why this policy was adopted; and explain why the policy was limited to children under six. What is the source of your statement (as reported in the article) that "a strong recommendation" to treat children with cryoprecipitate existed in the UK for a number of years before 1985?*

As stated in The Irish Times, it was our policy to use locally produced cryoprecipitate to treat young children with haemophilia A. These children were considered too young to start home therapy and cryoprecipitate was

easily administered in hospital. Most children over the age of 6 had good enough veins and parental expertise to be started on home therapy.

I cannot remember the source (if any) of a "strong recommendation". It was simply best practice among UKHCDO members.

19. *To what extent, and why, were people with mild or moderate bleeding disorders treated with factor concentrates?*

This depended on the clinical indication, for instance severe bleeds or dental extractions/surgery. Concentrates were used until the introduction of DDAVP for haemophilia A patients.

20. *What viruses or infections, other than HIV, HCV and HBV, were transmitted to patients at the Centre in consequence of the use of blood products?*

To my knowledge, none.

Section 3: Knowledge of, and response to, risk

General

21. *When you became a consultant paediatrician in 1970/71, what did you know and understand about the risks of infection associated with blood and/or blood products? How did your knowledge and understanding develop over time?*

General knowledge in 1970/71 concerned serum hepatitis. Knowledge developed over time with the advent of hepatitis B vaccination and discovery of hepatitis C virus.

22. *In 'The Reunion' you stated that you were aware that there were dangers in blood "from the very beginning", stating that "From the Second World War when blood was of course used as whole blood or albumin; it was well known that there were hepatitis viruses within blood, and we saw patients with abnormal liver function tests from a very early age". Do you have anything to add to that statement?*

No.

23. *What advisory and decision-making structures were in place, or were put in place, at the Centre and/or within the area covered by the Northern Regional Haemophilia Service, to consider and assess the risks of infection associated with the use of blood and/or blood products?*

All patients were followed up individually at three monthly intervals and checked for side effects including risk of infection as known at the time. Routine liver function tests and physical examination for hepatosplenomegaly were carried out.

24. *What was your understanding of the relative risks of infection from (i) the use of commercially supplied blood product and (ii) the use of NHS blood products?*

This changed with time. Commercially supplied blood products used by the Centre were all licensed. They were only used because of the continued shortage of NHS blood products.

25. *What decisions and actions were taken by the Centre and by you to minimise or reduce exposure to infection?*

This was outside the Centre's control. Only licensed products were used.

Hepatitis

26. *When you became a consultant paediatrician in 1970/71, what was your knowledge and understanding of the risks of the transmission of hepatitis, including hepatitis B and NANB hepatitis (hepatitis C), from blood and/or*

blood products? How did that knowledge and understanding develop over time?

See 23. It became known that serum hepatitis covered hepatitis B and hepatitis C and possibly other viruses.

27. *In your contribution to the Witness Seminar held at the Wellcome Institute on 10 February 1998, you stated that 'We knew from the beginning that we were transmitting disease, we knew that there was something called serum hepatitis, we now know it as hepatitis B, after the Australian antigen was discovered. We knew that hepatitis B was in those concentrates and the companies knew that hepatitis B was in those concentrates. The first outbreaks of hepatitis B in the haemophilia population of the United Kingdom were because of dumping of concentrates which would not have passed the Food and Drug Administration (FDA) regulations in the United States of America. Even that did not blunt the enthusiasm for treatment, because we moved on ... to home therapy and from there to prophylaxis and to the prevention of haemophiliac arthropathy. We also knew that there was another virus in the concentrates which we then called non-A and non-B hepatitis and we now know as hepatitis C but all the evidence then from around the world then was that this too produced a chronic disorder which might result in ill-health in a few people."*

27(a) *Is it your understanding that serum hepatitis is synonymous with hepatitis B (as opposed to a term encompassing both hepatitis B and NANB hepatitis)? If so what is the basis for that understanding?*

No, we did not know at that time that serum hepatitis was a generic term encompassing other viruses than B.

27(b) *Did you tell your patients that they were being treated with dumped concentrates that would not have passed the FDA regulations in the USA? If not, why?.*

Patients were given all available information available to us at the time.

27(c) *Why did your knowledge of hepatitis and the dumping of concentrates not "blunt the enthusiasm for treatment"?*

At the time that treatment started the average age of death in severe haemophilia A was 35 years and patients could expect on average 35 major bleeds a year. We therefore felt that the need for treatment was overwhelming.

28. *In your Draft Personal Record (p. 26) you stated that "by the end of the decade [i.e. the 1970s] we were in no doubt that haemophiliacs exposed to multi donor Concentrates were inevitably infected with non A non B hepatitis, and that a substantial proportion of them could go on to develop chronic liver disease"*

28(a) *Did you tell your patients who were being treated with factor concentrates that they were inevitably infected with non A non B hepatitis?*

Yes

28(b) *If not, why?*

See a.

28(c) *Did you tell your patients who were being treated with factor concentrates that a substantial proportion of them could go on to develop chronic liver disease?*

Yes

28(d) *If not, why?*

See c.

29. *What if any enquiries and/or investigations did you carry out or cause to be carried out in respect of the risks of transmission of hepatitis? What information was obtained as a result?*

All severely affected patients were followed up individually. All had physical examination for hepatosplenomegaly and other abnormalities. All had liver function tests performed. All patients were informed of the results.

30. *What if any actions did you take to reduce the risk to patients of being infected with hepatitis (of any kind)?*

We only used licensed products. When it became available all patients testing negative for hepatitis B were offered vaccination. In addition, there was a strict protocol within the Centre for the management of needle stick injuries, to cover possible infection with hepatitis. All patients and those responsible for the administration of intravenous therapy were told to report accidents immediately and were offered gammaglobulin in order to prevent transmission. It follows that everyone concerned knew of the possible transmission of hepatitis.

31. *What was your understanding of the nature and severity of the different forms of blood borne viral hepatitis and how did that understanding develop over time?*

This evolved with time. We knew hepatitis A was not transmitted. B was eventually countered by vaccination. Non-A Non-B eventually became hepatitis C.

HIV and AIDS

32. *What was your knowledge and understanding of HIV (HTLV-III) and AIDS and in particular of the risks of transmission from blood and blood products? How did your knowledge and understanding develop over time?*

Please find appended timeline for HIV and haemophilia in the United Kingdom (Exhibit WITN0841014).

33. *How and when did you first become aware that there might be an association between AIDS and the use of blood products?*

34. *What steps did you take in light of that awareness?*

35. *What if any enquiries and/or investigations did you carry out or cause to be carried out in respect of the risks of transmission of HIV or AIDS? What information was obtained as a result?*

All this has been well documented and is in my Personal Record. (WITN0841007)

36. *In your contribution to the Witness Seminar held at the Wellcome Institute on 10 February 1998, you stated (p. 65) that 'With HIV we realised that we had got a problem after the description of the first cases in 1981. The Haemophilia Centre directors thought very long and hard, and thought that one in a thousand people who had been transfused with contaminated products would develop AIDS. One in a thousand. Again it was something to be concerned about, but perhaps to put on one side in favour of continuing treatment.".*

36(a) *What was the basis for the view of the Haemophilia Centre directors that one in a thousand people transfused with contaminated products would develop AIDS?*

This came from initial findings in the United States.

36(b) *Did you tell your patients of the considered view of the Haemophilia Centre directors that one in a thousand people transfused with contaminated products would develop AIDS?*

Yes

36(c) *You describe the threat of AIDS as "something to be concerned about, but perhaps to put on one side in favour of continuing treatment". Do you accept that the decision as to whether to "put on*

one side" the risk of AIDS "in favour of continuing treatment" was a decision for individual patients to make rather than doctors?

All my patients were fully informed and all decisions for treatment were made on an individual basis.

37. *What if any actions did you take to reduce the risk to your patients of being infected with HIV?*

Heat treatment when it became available.

38. *Did you continue to use factor concentrates to treat patients, after becoming aware of the possible risks of infection of HIV? If so, why?*

Well documented, also available in my Personal Record.

Response to risk

39. *Did you take steps to ensure that patients were informed and educated about the risks of hepatitis and HIV? If so, w at steps?*

Yes. Centre always had open door policy. In addition there were regular meetings, Haemophilia Society bulletins and newsletters (Exhibit WITN0841015) and residential weekends for patients and their families (Exhibit WITN0841016 Please also see Exhibit WITN0841017, a booklet produced by Centre staff to help families with HIV infection.

40. *What consideration did you give to the use of heat-treated products prior to the meeting of Haemophilia Reference Centre Directors on 1O December 1984?· Did you (a) agree with and (b) follow the recommendations made at that meeting, including the recommendation to use heat-treated concentrates?*

Recommendations for heat treatment were immediately enforced at the Centre.

41. *Do you consider that heat-treated products should have been made available earlier? If not, why?*

No. There were two reasons: (1) we did not know the side effects of heat treatment; and (2) it was known that heat treatment reduced the yield of factor VIII and therefore the need for more donations.

42. *Do you consider that your decisions and actions and those of the Centre in response to any known or suspected risks of infection were adequate and appropriate? If so, why? If not, please explain what you accept could or should have been done differently.*

Yes. Sources of information included both surveillance in the United Kingdom and the United States (Centers for Disease Control). I do not accept that we could have done anything differently at the time.

43. *What decisions or actions by you and/or by the Centre could and/or should have avoided, or brought to an end earlier, the use of infected blood products?*

None without self-sufficiency, and even then it is known that the incidence of hepatitis is the same in multi-transfused patients whether or not NHS or commercial concentrates are used.

44. *Did you revert to treatment with cryoprecipitate for some or all of your patients? If so, how did you decide which patients would be offered a return to cryoprecipitate and which would not? If not, why not?*

Yes, but only when recommended.

45. *What actions or decisions or policies of other clinicians or other organisations, within your knowledge, played a part in, or contributed to, the scale of infection in patients with bleeding disorders? What, if anything, do you consider could or should have been done differently by these others?*

We worked closely with the United Kingdom Haemophilia Centre Directors Organisation and with our colleagues in centres throughout the world, most especially in Centers for Disease Control in America.

46. *Do you consider that greater efforts should have been made to inactivate viruses in blood or blood products prior to 1980? If so, who should have made or coordinated those efforts and what steps should have been taken and when? If not, why?*

In retrospect, earlier heat treatment might have reduced the incidence of hepatitis but it might also have increased the risk of side effects from the need for measures to counter the loss of yield.

47. *In your contribution to the Witness Seminar held at the Wellcome Institute on 10 February 1998, you stated (p. 72) that you "know that as well as hepatitis B, manufacturers knowingly imported blood products which were known to be HIV positive. I also know that within the European community, and I have documentary evidence, there has been re-labelling of blood products, unknown to the Committee on the Safety of Medicines". A little later you added that "the background of it is again what I refer to as secrecy".*

47(a) *Please provide full details of the factual basis for your understanding that manufacturers knowingly imported blood products which were known to be HIV positive.*

47(b) *Please provide full details of the factual basis for your understanding that there had been re-labelling of blood products unknown to the Committee on the Safety of Medicines.*

47(c) *Please provide to the Inquiry the documentary evidence that you hold to show that there had been such re-labelling of blood products.*

47(d) *What did you mean by there being a background of "secrecy"?*

I believe that all this information has already been submitted in my-Personal Record. To my knowledge the Inquiry already has the documentary evidence that you ask for, especially the Memorandum concerning a visit to a fractionation facility in Lessines, Belgium.

48. *You are reported (see Irish Times, July 13th 2001) as having told the Lindsay Tribunal that you were informed by a representative of Armour Pharmaceuticals that donors to its Factorate product had been individually tested for HIV when this was not the case. Is this correct? Please provide details of the discussion that you had with the representative of Armour Pharmaceuticals, including when it took place, the name of the representative and what was said. Did you rely upon this information when taking decisions about what products to use? When and how did you learn that the statement was not true?*

I have no recollection of talking to a representative of Armour Pharmaceuticals about this, or of learning that any statement discussed was not true.

49. *The same article reports that you had concerns about the safety of Factorate from late 1985, that in February 1986 you presented a paper at an AIDS conference in Newcastle (see further question 157 below) raising doubts about the efficacy of commercial heat-treatment in killing HIV and that in March 1986 you wrote to the UK Committee on the Safety of Medicines recommending that Factorate be withheld from further distribution. Is this correct? Please explain why you had concerns about this particular product and give details of the steps that you took to raise or share your concerns. (I enclose a copy of a letter from you to the Committee on the Safety of Medicines dated 18 February 1986).*

It is correct that I questioned the efficacy of heat treatment in respect to some products in February 1986. This knowledge was individual from colleagues who had reported seroconversions. The knowledge was

eventually published and gave rise to withdrawal of one particular product that was implicated in these seroconversions.

I did have in my possession but can no longer locate a document Action Items from Armour 1985. This minute reveals the state of knowledge within Armour at the relevant time.

Section 4: Treatment of patients at the Centre

Provision of information to patients

50. *What information did you provide or cause to be provided to patients with a bleeding disorder (and to any patients who did not have a bleeding disorder but were treated with blood products for other conditions) about the risks of infection in consequence of treatment with blood products (in particular, factor concentrates), prior to such treatment commencing? Please detail whether and if so how this changed over time.*

As stated several times already and within my Personal record, all patients and their families had access to comprehensive care at any time. This is set out in several publications including “Living with Haemophilia” and “AIDS and the Blood”.

51. *Do you accept that patients should have been informed that it was well known that there were hepatitis viruses within blood?*

All patients were informed individually about the risks of hepatitis.

52. *You referred in The Reunion' to there being "leaflets" "with every bottle" and stated that "those leaflets from a very early stage stated that there was a risk of hepatitis". Did you draw the attention of your patients to those leaflets? Did you explain to your patients that there was a risk of hepatitis? What information did you give them about hepatitis?*

Yes. All patients had access to these leaflets. Yes, each patient or parent had the risk of hepatitis explained and Yes, each patient was given up to date information about hepatitis.

53. *In the Reunion' you asserted that "we did advise all our patients and we did have informed consent" and that "everybody, patients and staff, knew the status of the liver function which reflected the hepatitis virus". Please explain the factual basis for the assertion and provide details of the discussions that you had with patients about risks and about liver function tests and their significance.*

Informed consent was part of the counselling of every patient. All severely affected patients were followed up on a three-monthly basis, this follow-up including liver function tests, physical examination and full discussion of the findings.

54. *You· also stated in The Reunion' that "I have the book where the nurses rigorously recorded the names of the patients and the_ date that they gave their consent for the testing". Please provide details of the "book" which you are describing and make it available to the Inquiry for inspection. If you no longer have this "book", please explain what has happened to it.*

I no longer have the book and have no idea what has happened to it. However, the book did exist and it did list every individual patient who had given informed consent.

55. *What information did you provide or cause to be provided to patients about alternatives to treatment with factor concentrates? Please detail whether and if so how this changed over time.*

All patients were counselled both individually and in groups about alternatives to treatment. Delegates from the patient community were involved in decisions about the purchase of concentrates.

56. *What information did you provide or cause to be provided to patients before they began home treatment/home therapy?*

All patients/parents/families were fully counselled before home therapy by me, by the Clinical Nurse Specialist or her deputy and by the Social Worker.

57. *When did you first discuss AIDS or HIV (HTLV-111) with any of your patients?*

All patients or parents or families were informed about HIV/AIDS at the first opportunity and thereafter.

58. *Please describe how and when you learned that patients under your care had been infected with HIV.*

This is well documented and described in Exhibit WITN0841018.

59. *You asserted in The Reunion' (in the context of a discussion about infection with HIV) that "we now know that most of the haemophilia population who were infected were infected in the mid to late 70s". Do you maintain this statement? Please note that in a letter to Dr Donaldson dated 23 February 1988 (enclosed), you asserted that "Retrospective testing of serum which had been stored down from a cohort of haemophilic patients now known to be HIV antibody positive shows that all were sero-negative in late 1980/mid 1981. From this and other data we think our patients became infected in late 1981/82 at a time when our average factor VIII usage was the same as that for the UK as a whole." What is the factual basis for the view stated in this letter that your patients became infected in late 1981/82?*

I apologise for any confusion. From memory, initially we thought that early 1980s was the point of infection, but retrospective testing, from memory, principally at the Royal Free Hospital, showed that seroconversion occurred earlier, around 1978/79.

60. *How and when were patients told that they had been, or might have been, infected with HIV? What information was given to them about the significance of a positive diagnosis? Did you tell patients to keep their infection a secret?*

All patients were seen individually once their results were known, and as soon as possible. We did not tell patients to keep their infection a secret but

counselled against broadcasting the fact that there was a positive result because of the publicity at the time.

61. *Please provide details of the group meetings and weekend gatherings to which you refer in 'The Reunion', at which you say that patients were provided with information and able to ask questions.*

Already answered.

62. *What was the Centre's /your policy in relation to testing partners/family members of people known or suspected to be infected with HIV? Under what circumstances were tests carried out?*

All partners/family members were offered testing individually. From memory, only one partner consistently requested not to be tested. Ironically, this partner went on to complain that we did not ask for informed consent.

63. *What if any information or advice did you provide to partners or family members of people that were at risk of infection with HIV or were infected with HIV?*

All partners/family members were given full information in accordance with knowledge at the time.

64. *How many patients at the Centre were infected with HIV? (Please note that in 'The Reunion' you stated that of 99 patients with haemophilia A, 78 were HIV positive. You also stated that 90% of those had died).*

(See WITN0841018).

65. *On 17 February 1986 (letter enclosed) you wrote to fellow centre directors stating that you had asked for the help of the PHLS/CDSC "in order to try and establish why we appear to be so vulnerable compared to the rest of the country". Please explain what investigations were undertaken as a result of you asking for help and what was stablished.*

Initially we thought that we were vulnerable and from memory this was because of the incidence of lymphoma. However, later results showed that

this impression was false and that that initial impression had been suggested by earlier testing than most centres.

Please also see the report (Exhibit WITN0841019) to Dr Donaldson dated 23 February 1988 regarding factor VIII usage in the Northern Region.

66. *Were patients infected with hepatitis B informed of their infection and if so how? What information was provided to patients infected with hepatitis B about the infection, its significance, prognosis, treatment options and management?*

Each patient had been tested for hepatitis B and when appropriate, offered hepatitis B vaccination. All this was done with full discussion of the significance, prognosis, treatment options and management.

67. *How many patients at the Centre were infected with hepatitis B?*

I no longer have this knowledge.

68. *Were patients infected with NANB hepatitis informed of their infection and if so how? What information was provided to patients infected with NANB hepatitis about the infection, its significance, prognosis, treatment options and management?*

As already stated, each individual patient/parent was fully informed with regard to infection with NANB hepatitis, its significance, prognosis, treatment options and management.

69. *When did the Centre begin testing patients for hepatitis C? How were patients told of their diagnosis of hepatitis C? What information was provided to patients infected with hepatitis C about the infection, its significance, prognosis, treatment options and management?*

As soon as a test for hepatitis C became available, testing was initially through the good service of Dr Tedder in London and later, Dr Codd in Newcastle. All patients were told individually about diagnosis and were fully informed thereon as knowledge about infection developed.

70. *How many patients at the Centre were infected with hepatitis C?*

I cannot remember how many patients were infected with hepatitis C.

71. *Were the results of testing for HIV and hepatitis (of all kinds) notified to patients promptly, or were there delays in informing patients of their diagnosis? If there were delays in informing patients, explain why.*

All results were notified promptly, at least at the nearest follow-up clinic. To my knowledge there were no delays in informing patients.

72. *To what extent, if at all, did you take into account the public health implications of HIV, AIDS, hepatitis B and NANB hepatitis/hepatitis C, when taking decisions as to what information or advice to provide to patients or what treatment to offer patients?*

All knowledge relating to these viruses took account of the public health implications, but all knowledge was tailored individually to patients/parents/families as was available treatment.

73. *What information was provided to patients about the risks of other infections?*

All patients/parents/families had full knowledge about risk of all infections as we knew it.

74. *What information was provided to patients about the risks of infecting others?*

Fully confidential information was provided to all patients individually and their partners.

Consent

75. *How often were blood samples taken from patients attending the Centre? What information was given to patients about the purposes for which blood samples were taken? Did you obtain patients' informed consent to the storage and use of those samples?*

All patients with severe haemophilia were followed up at three monthly individuals when blood was taken. From memory this blood was used to test for inhibitors, liver function tests, full blood count and any antibodies when tests were available. All examinations and blood sampling were conducted with patients' informed consent.

76. *Were patients under your care treated with factor concentrates or other blood products without their express and informed consent? If so, how and why did this occur? What was your approach to obtaining consent to treatment? If it is your position that patients did give express and informed consent to treatment with factor concentrates, please explain the basis for that position.*

No. Each patient or parent gave express and informed consent to every treatment and this was recorded.

77. *Were patients under your care tested for HIV or for hepatitis or for any other purpose without their express and informed consent? If so, how and why did this occur? What was your approach to obtaining consent for testing?*

No. Consent was an integral part of individual counselling.

PUPS

78. *Detail all decisions and actions taken by you or with your involvement with regard to a category of people referred to as 'previously untreated patients' (PUPS).*

The follow-up of previously untreated patients (PUPS) was considered essential as, if they required treatment it had to be established whether or

not the said treatment resulted in seroconversion. This was especially important as there was no animal model to test newer forms of treatment. In the simplest case, this was a method of testing to see whether heat treatment was effective or not in removing the threat from hepatitis/HIV.

Research

79. *Please detail all research studies that you were involved with during your time as a consultant at, or director of; the Centre. In relation to those research studies that could be relevant to the Inquiry's Terms of Reference, please:*

79(a) *describe the purpose of the research;*

79(b) *explain the steps that were taken to obtain approval for the research;*

79(c) *explain what your involvement was;*

79(d) *identify what other organisations or bodies were involved in the research;*

79(e) *state how the research was funded and from whom the funds came;*

79(f) *state the number of patients involved;*

79(g) *provide details of the steps taken to inform patients of their involvement and seek their informed consent; and*

79(h) *provide details of any publications relating to the research.*

All research at the Centre was carried out with reference to the hospital Ethics Committee. All research was either with the Haemophilia Centre Directors Organisation or the Medical Research Council.

80. *What do you understand to be the ethical principles that should guide research? Did you apply those principles to the research studies referred to above and if so how? If not, why not?* ·

As 80. No research was carried out without ethical approval.

81. *Were patients involved in research studies without their express consent? If so, how and why did this occur?*

No.

82. *Was patient data (anonymised, de-identified or otherwise) used. for the purpose of research or for any other purpose without their express consent? If so, what data was used and how and why did this occur?*

No. In the context of "research" the Oxford Returns provided a regular update of treatment and allowed comparison with other regions.

83. *Was patient data (anonymised, de-identified or otherwise) shared with third parties (e.g. UKHCDO or Oxford Haemophilia Centre)? If so how and why did this occur and what information was provided to whom?*

Yes. Through the Oxford Returns, information shared throughout United Kingdom and within articles in the medical literature.

84. *Please provide details of any articles or studies that you have published insofar as relevant to the Inquiry's Terms of Reference.*

Already referenced in my Personal statement. Additional publications referenced and appended at the end of this questionnaire.

Treatment of patients who were infected with HIV and/or hepatitis

85. *How was the care and treatment of patients with HIV/AIDS managed at the Centre? What steps were taken to arrange for, or refer patients for, specialist care? What treatment options were offered over the years to those infected with HIV? What information was provided to patients about the risks and benefits of specific treatments and about side effects?*

See AIDS and the Blood (Exhibit WITN0841020). See "The Counselling of HIV Antibody Positive Haemophiliacs" (Exhibit WITN0841021). See "HIV Infection and Haemophilia" (Exhibit WITN0841022). In addition, all editions of "Living with Haemophilia" contain the information requested.

86. *What follow-up and/or ongoing monitoring was arranged in respect of patients who were infected with HIV?*

See 86.

87. *How was the care and treatment of patients with hepatitis B managed at the Centre? What steps were taken to arrange for, or refer patients for, specialist care? What treatment options were offered over the years? What information was provided to patients about the risks and benefits of specific treatments and about side effects?*

The Co-Director of the Centre had specialist knowledge on liver care and there was close liaison with the Liver Unit at the Newcastle Freeman Hospital. Otherwise, as 86.

88. *What follow-up and/or ongoing monitoring was arranged in respect of patients who were infected with hepatitis B?*

As 86.

89. *How was the care and treatment of patients with NANB hepatitis managed at the Centre? What steps were taken to arrange for, or refer patients for, specialist care? What treatment options were offered over the years? What*

information was provided to patients about the risks and benefits of specific treatments and about side effects?

As 88.

90. *How was the care and treatment of patients with hepatitis C managed at the Centre? What steps were taken to arrange for, or refer patients for, specialist care? What treatment options were offered over the years? What information was provided to patients about the risks and benefits of specific treatments and about side effects?*

As previously.

91. *What follow-up and/or ongoing monitoring was arranged in respect of patients who were infected with hepatitis C?*

As previously.

92. *What arrangements were made for the care and treatment of children infected with HIV and/or hepatitis? How did those arrangements differ (if at all) from the arrangements made for adults?*

As previously. All children were followed up individually with their parents and information shared as appropriate to their age.

93. *What if any arrangements were made to provide patients infected through blood products with counselling, psychological support, social work support and/or other support?*

Comprehensive Care was initiated at the Newcastle Haemophilia Centre and is fully recorded in the literature including "Living with Haemophilia". Please also see the winning essay from our Social Workers appended as Exhibit WITN0841023.

94. *How did the Centre use the £60,000 that was allocated by the Department of Health and Social Security to each Haemophilia Reference Centre to help with counselling of patients infected with HIV?*

From memory I have no recollection of a specific £60,000 being allocated to us. But if it was it would have been to help within the Social Work Department.

Records

95. *What was the Centre's policy or practice as regards recording information on death certificates when a patient had been infected with HIV or hepatitis?*

Please see Exhibit WITN0841024. In view of the risk of publicity, each individual death involving HIV/AIDS was referred to the Coroner's Officer.

96. *What were the- retention policies of the Centre with regards to medical records during the time you were director?*

Retention of medical records was a matter for the Medical Records Department in the Hospital

97. *Did you maintain separate files for some or all patients? If so, why; where were those files located; and where are those files now?*

Only with regard to litigation. To my knowledge all these files are in the hands of particular solicitors apart from one set of records (see 99).

98. *Did you keep records or information (e.g. information being used for the purpose of research) about any of your patients at your home or anywhere other than the Centre? If so, why, what information and where is that information held now?*

Yes, because of ongoing litigation I hold the records of one patient at home. That is because I retired 20 years ago but the threat of litigation continues.

99. *Do you still hold records or information about any of your patients? If so, explain why and identify the records or information that you still hold.*

As above.

Section 5: Work with Treloar's and Oxford Haemophilia Centre

100. *Please describe your involvement with Lord Mayor Treloar College/Treloar's ("Treloar's") and/or with the care and treatment of boys attending Treloar's.*

We referred some boys to Lord Mayor Treloar and later to Welburn Hall School.

101. *Did you recommend that patients under your care attend Treloar's and/or refer them to Treloar's? If so:*

101(a) *How many patients did you recommend or refer to Treloar's?*

I cannot remember the numbers but they were small.

101(b) *What prompted the recommendation(s) or referral?*

This was prompted by difficulty parents were having in both treating haemophilia and maintaining a good education for the child.

101(c) *What involvement did you have in the arrangements for them to attend Treloar's?*

I made recommendations which were then followed up by the relevant Council departments.

101(d) *What involvement did you have with the ongoing care and treatment of boys attending Treloar's?*

Ongoing care and treatment became the responsibility of the doctors at Lord Mayor Treloars. There was full communication about this care and treatment between Treloars and the Centre

102. *Please describe any research and/or trials and/or experimental treatment that you are aware of involving pupils at Treloar's, including any involvement that you had in such research/trials/treatment.*

Only in as much as sharing of information.

103. *As far as you are aware, were the pupils at Treloar's treated differently · to other people with bleeding disorders? If so, in what respects and why?*

No.

104. *Did you recommend that patients under your care attend, or make a referral to, any other residential school or college (such as Welburn Hall)? If so:*

Yes

104(a) *How many patients did you recommend or refer to other residential schools or colleges?*

I cannot remember but the number was small.

104(b) *What prompted the recommendation(s) or referral?*

As above.

104(c) *What involvement did you have in the arrangements for them to attend the school or college?*

As above.

104(d) *What involvement did you have with the ongoing care and treatment of boys attending the school or college?*

Ongoing follow-up in Newcastle plus regular school visits.

105. *Please detail your involvement with the Oxford Haemophilia Centre and with any research or studies undertaken by or with Dr Rizza.*

Oxford Haemophilia Centre was crucial in the development for the successful treatment of the haemophilia. Dr Rizza was a valued colleague

with regard to this development. Knowledge about treatment for haemophilia within the United Kingdom was dependent on the Oxford Returns.

Section 6: Self-sufficiency

106. *In December 1974 the Department of Health announced additional funding with the primary aim of making the NHS self-sufficient in Factor VIII blood products within two to three years.*

106(a) *Were you aware of this announcement at that time?*

106(b) *What role, if any, did you play in any arrangements made at the Centre or within the northern region, in response to that announcement?*

See earlier statement. No role played at Centre.

107. *What did you understand the term "self-sufficiency" to mean in 1974/1975? In particular, did you understand it to mean self-sufficiency in providing Factor VIII blood products prophylactically, or solely in response to bleeding incidents?*

This question is non-sensical. Under one definition the provision of factor VIII blood products prophylactically covers dental extractions and surgery. We understood self-sufficiency to mean the provision of enough factor VIII to cover all eventualities.

108. *Did your understanding of what "self-sufficiency" meant change at any time? If so, when and why?*

As 108.

109. *What was your understanding of how others defined "self-sufficiency"? Please answer by reference to (i) those involved in the supply of plasma, (ii) those involved in the production of blood products, (iii) clinicians prescribing blood products, (iv) patients using blood products (and their families), and (v) those responsible for managing relevant health authorities and bodies.*

As 108. There was discussion at the time amongst all these parties with regard to "patients living within the realms of their disorder" and prophylaxis. Increasing knowledge has demonstrated unequivocally that the majority of patients can live normal lives with reasonable amounts of treatment given prophylactically. Similarly, the worst thing that a patient with severe haemophilia can do is live within the bounds of his disability. Exercise and good health are essential prerequisites of modern haemophilia treatment.

110. *What, if any, efforts were made to ensure that all of the groups mentioned in the previous question shared a common understanding of what "self-sufficiency" meant?*

See 110.

111. *How were estimates made of how much Factor VIII-blood product would be required for use in England and Wales? In particular:*

111(a) *What was your role in making such estimates, and how did this change overtime?*

111(b) *What was the role of UKHCDO and how did this change over time?*

111(c) *What assumptions would underpin the estimates (including assumptions as to how the blood products would be used)?*

111(d) *How would the estimate be made (e.g'. by whom were they made, when and through what process)?*

111(e) *How were the estimates shared with' other interested parties?*

111(f) *How did any of these processes change over time?*

I have no accurate memory of the figures required here. However, they were arrived at very carefully in discussion with colleagues using the Oxford Returns.

112. *How were annual figures derived for how much Factor VIII blood product had been used over the course of a year?*

112(a) *What was your role in providing such figures, and how did this change over time?*

112(b) *What was the role of UKHCDO and how did this change over time?*

112(c) *How would the calculations be made (e.g. by whom were they made, when, through what process and using what data)?*

112(d) *How were those figures broken down geographically (e.g. by country, region or any other unit)?*

112(e) *How were the figures shared with other interested parties?*

112(f) *How did any of these processes change over time?*

As 112.

113. *Were there significant differences between the estimates that were made and actual use? If so, why?*

I have no recollection of significant differences.

114. *It may be suggested that England and Wales never achieved self-sufficiency of Factor VIII blood products, in the sense that clinicians were always reliant on commercially imported products to meet the actual demand of patients for such products.*

114(a) *Is this correct, to the best of your knowledge?*

114(b) *If so, why, in your opinion, was self-sufficiency was never achieved?*

114(c) *If, in your view, self-sufficiency was achieved, when was it achieved and why it was not achieved earlier?*

Clinicians were only reliant on commercially imported products because there was insufficient NHS product. Please see Exhibit WITN0841025.

115. *It may be suggested that a significant contributory factor to England and Wales in not achieving self-sufficiency (or not doing so earlier) was a failure by haemophilia clinicians to provide timely and accurate estimates of future demand for Factor VIII blood products. In particular, it may be suggested that haemophilia clinicians failed to identify the foreseeable increase in use of such products once they became available. How would you respond to these suggestions?*

These suggestions are not correct. Oxford Returns were published and there was open discussion over time.

116. *If self-sufficiency had been achieved in Factor VIII products, what, in your view, would have been the effect on the numbers of patients infected with (i) HBV, (ii) HCV, and (iii) HIV. Please comment on when self-sufficiency would have needed to be achieved (in your view) in order for any material difference to have been made in respect of each of these viruses.*

Sadly there would have been little if no effect on numbers of patients infected. See Exhibit WITN0841026.

117. *It may be suggested that England and Wales did achieve self-sufficiency in respect of Factor IX blood products. To the best of your knowledge, is this correct? Please explain your answer.*

I cannot recall the specifics of factor IX therapy.

118. *If self-sufficiency in respect of Factor IX blood products was achieved, did you nonetheless use commercially produced products in preference to domestically produced products? If so, why?*

Again, I cannot recall the question of self-sufficiency with factor IX. I do remember there was discussion about whether heat treated factor IX could cause difficulties with thrombosis, but I do not recall whether this was used as an argument for using specific products

Section 7: Blood services

119. *Please outline the interactions and dealings you had with the blood services, whether on a regional or national level, in your capacity as director of the Centre.*

We had regular meetings/discussions with the Director of the Regional Blood Transfusion Service. In addition, the Blood Transfusion Service was always represented at regular UKHCDO meetings.

120. *What if any consideration was given to increasing production of cryoprecipitate, or producing a product with lower risk, in response to the risks associated with factor products, and what if any involvement did you have with any blood service (regionally or nationally) in relation to this?*

The question of producing more cryoprecipitate was discussed, but this would have led to a reduced source plasma for NHS factor concentrate and (apart from its recommendation for children) was dismissed.

121. *What if any discussions or meetings or interactions did you have with any blood service (regionally or nationally) in relation to:*

121(a) *the risk of infection with hepatitis from blood products;*

121(b) *the risk of infection with HIV/AIDS from blood products;*

121(c) *the steps to be taken to reduce the risk of infection?*

We were always part of the discussion with the BTS.

122. *What if any involvement did you have with any decisions or actions taken by any blood service (regional or national) in response to the risks arising from blood and blood products?*

Decisions and actions were taken specifically by the BTS and not by the Centre.

Section 8: UKHCDO

123. *Please describe your involvement with UKHCDO (including any of its working parties, committees or groups).*

As Director of the Newcastle Haemophilia Centre I was a member of the UKHCDO and was Chair of the Home Therapy Working Party.

124. *During the period that you were involved with UKHCDO, please outline:*

124(a) *the purpose, functions and responsibilities of UKHCDO, as you understood them;*

124(b) *the structure, composition and role of its various committees or working groups;*

I am sure that you already have specific answers to these questions.

124(c) *the relationships between UKHCDO and pharmaceutical companies;*

There was no formal relationship at any time between UKHCDO and pharmaceutical companies.

124(d) *how decisions were taken by UKHCDO; Decisions were minuted after full discussion.*

124(e) *how information or advice was disseminated by UKHCDO and to whom;*

By individual letter to the Centres from Oxford and publication.

124(f) *any policies, guidance, actions or decisions of UKHCDO in which you were involved and which relate to:*

Again, I am sure that you have answers to these questions. All were covered within discussions that I can remember within UKHCDO, and all were notified to centres both individually and in publications.

(i) the importation, purchase and selection of blood products;

(ii) the manufacture of blood products;

(iii) self-sufficiency;

(iv) alternative treatments to factor products for patients with bleeding disorders;

(v) the risks of infection associated with the use of blood products;

(vi) the sharing of information about such risks with patients and/or their families.

(vii) obtaining consent from patients for the testing and storage of their blood, for treatment and for research;

(viii) heat treatment;

(ix) other measures to reduce risk;

(x) vCJD exposure; and

(xi) treatments for HIV and hepatitis C.

Section 9: Pharmaceutical companies/medical research/clinical trials

125. *Have you ever provided advice or consultancy services to any pharmaceutical company involved in the manufacture and/or sale of blood products? If so, please list the names of the companies and give details of the advisory or consultancy services that you provided.*

On two occasions as stated in my Personal Record. The first was early in my career when I was offered the job of Medical Director by Baxter Travenol and worked with them in Belgium for a number of months with full approval of my health authority and knowledge of UKHCDO. The second was a short period when I inspected Revlon/Armour facilities in the United States. The first resulted in a textbook of haemophilia treatment also translated into Japanese. The second produced a confidential report on facilities in the United States.

126. *Have you ever received any pecuniary gain in return for performing an advisory/consultancy role for a pharmaceutical company involved in the manufacture or sale of blood products? If so, please provide details.*

Only as regards 125. I was individually responsible for drafting conflict of interest documents for both UKHCDO and the World Federation of Hemophilia.

127. *Have you ever sat on any advisory panel, board, committee or similar body, of any pharmaceutical company involved in the manufacture or sale of blood products? If so, please provide details of your involvement and of any financial or other remuneration you received.*

No.

128. *Have you ever received any financial incentives from pharmaceutical companies to use certain blood products? If so, please provide details.*

No.

129. *Have you ever received any non-financial incentives from pharmaceutical companies to use certain blood products? If so, please provide details.*

No.

130. *Have you ever received any funding to prescribe, supply, administer, recommend, buy or sell any blood product from a pharmaceutical company?*

No.

131. *What regulations or requirements or guidelines were in place at the time concerning declaratory procedures for involvement with a pharmaceutical company? If you were so involved, did you follow these regulations, requirements and guidelines and what steps did you take?*

There were hospital guidelines which were followed in the prescription of all products used in the Centre.

132. *Have you ever undertaken medical research for, or on behalf of, or in association with, a pharmaceutical company involved in the manufacture or sale of blood products? If so; please provide details.*

Only with regard to 125.

133. *Have you ever provided a pharmaceutical company with results from medical research studies that you have undertaken? If so, please provide details.*

No.

134. *If you did receive funding from pharmaceutical companies for medical research, did you declare the fact that you were receiving funding and the source of the funding to your employing organisation?*

Not relevant.

135. *In January 1979 you undertook a visit to the Hyland production facility in Lessines and to the Swiss Red Cross. What was the purpose of the visit? What. if any decisions or actions were taken in consequence of the visit?*

I did not make the visit referred to. I have no idea where this information comes from. It was not me. I suspect you are extrapolating from the document released with my personal statement which is appended (Exhibit WITN0841027).

136. *In September 1979, you had a meeting in Paris with Robert Taub and Wolfgang Marguerre, who were employed by the Revlon Health Care Group, in the course of which there was discussion about you becoming a consultant as well as discussion about you participating in a study of the new Factor VIII product being introduced by Armour. Please provide full details of the discussions that you had. What if any decisions or actions were taken in consequence of the meeting?*

Please see Exhibit WITN0841028.

Section 10: vCJD

137. *When and in what circumstances did you become aware of the risks of transmission of vCJD associated with the use of blood and blood products?*

138. *What if any steps did you take:*

138(a) *To put in place a process at the Centre for informing patients about possible exposure to vCJD?*

138(b) *To tell patients of possible exposure to vCJD?*

138(c) *To provide information to patients about the risks of vCJD?*

138(d) *To arrange for counselling, support and/or advice to be offered to patients who were being informed that they might have been exposed to vCJD?*

I have no recollection or record relating to vCJD as I retired in 2000.

Section 11: The Centre's involvement with the financial support schemes

139. *To what extent, during your time as director of the Centre, did the Centre and its staff inform patients about the different trusts or funds (the Macfarlane Trust, the Eileen Trust, the Macfarlane and Eileen Trust and the Caxton Foundation) which were set up to provide financial support to people who had been infected?*

At all times individual patients/families were informed about different trusts or funds. Only the Macfarlane Trust was involved before my retirement.

140. *Did the Centre have any policy or any guidance for staff members in relation to referring patients to the trusts and funds for support?*

Not to my knowledge. Patients were treated on an individual basis

141. *What kind of information did the Centre {whether through you or otherwise) provide to the trusts and funds about or on behalf of patients who were seeking assistance from the trusts and funds?*

Information was handled by the Social Workers in consultation with the rest of the team responsible for the care of patients/families.

142. *Did the Centre, or any of its staff (including you), act as a gateway for determining whether a particular patient met the eligibility criteria for the receipt of assistance from any of the trusts and funds? If so, please explain who set the criteria, what they were and how they were applied.*

Not to my knowledge.

143. *Was the Centre or any of its staff (including you) involved in determining applications made by patients for assistance from the trusts or funds? If so, please describe that involvement.*

I was only involved as a trustee of the Macfarlane Trust in discussion with fellow trustees. Please see below.

Section 12: Your involvement with the financial support schemes

144. *You were a Trustee of the Macfarlane Trust between 1988 and 1991. Please explain:*

144(a) *how you came to be appointed as a Trustee;*

I was appointed by the DHSS after a campaign I ran in conjunction with the Haemophilia Society for help for infected people with haemophilia.

144(b) *the functions that you carried out and the responsibilities that you held in this capacity.*

I carried out the responsibilities of a Trustee.

145. *In your Draft Personal Record for the HIV Haemophilia Litigation, you describe yourself as a DHSS-appointed Trustee. Please explain what was meant by this; whose interests you were representing in your role as a DHSS appointed Trustee; whether you received any instructions or guidance from the DHSS as to how to perform your role (and if so what instructions or guidance); and whether you had any reporting obligations to the DHSS.*

I understood that I was there as a Trustee with no commitment to DHSS. I received no instructions or guidance from DHSS and I had no reporting obligations to DHSS.

146. *Were you involved in the development of any criteria or policies of the Macfarlane Trust relating to eligibility for financial assistance or for determining applications? If so please provide details.*

From memory, development of all criteria and policies of the Macfarlane Trust was the responsibility of the Trustees, of which I was one.

147. *Did you provide advice to the Macfarlane Trust? If so please provide details.*

My prime responsibility was to provide accurate medical information to the other Trustees.

148. *Were you involved in assessing, approving and/or rejecting applications for assistance that were made to the Macfarlane Trust? If so please provide details.*

Yes in concert with my colleagues in the Trust.

149. *At a meeting of trustees on 2 May 1989 (MACF0000002_015):*

149(a) *It was recorded that trustees thought that in some cases further health evidence would be of value in assessing the strength of applications.*

Why was it thought that further evidence was sometimes necessary beyond the evidence that was provided by applicants?

The Trustees relied on up to date and accurate information on the medical condition of applicants, i.e. objective evidence was needed and as far as I could I provided this.

149(b) *You agreed to write to other Centre Directors to seek assistance about the provision of medical evidence. Please explain what assistance you requested and what responses were received, if any.*

Medical colleagues were very helpful in providing additional information in order that decisions could be made in specific cases.

150. *Please provide details of the Trust's "Mortgage Policy" (referred to, for example, in the meeting of 2 May), explaining how the policy was developed and applied. Please also address the following questions:*

150(a) *In the minutes of a meeting held on 24 October 1988 (MACF0000002_009, enclosed), trustees agreed with your proposal to support a specific case for mortgage assistance and decided to treat it as a "test case". Please provide details, to the extent that you are able, of your proposal and how and why the Trust decided to support this test case.*

150(b) *Please describe how and why the Trust decided to implement equity share arrangements to assist beneficiaries with house purchases and provide an overview of how this was managed (minutes of meeting on 16 February 1989, MACF0000002_013, enclosed).*

150(c) *What was the "Newcastle case" that was discussed at the meeting on 16 February 1989?*

150(d) *Please explain why you were dissatisfied with the decision taken by Trustees at the meeting on 16 February 1989 such that you withdrew from the meeting.*

I cannot remember how the mortgage policy was developed, or of the details you require in a. and b. In the case of c., my memory is that there was a specific case who was in dire need of rehousing and- d., I had had long discussions in consultation with the specific family and was very disappointed that the decision against them was taken at the meeting referred to. I therefore withdrew.

151. *Please comment on why the Trust considered it could not be drawn into the compensation campaign by the Haemophilia Society (minutes of meeting on 20 November 1989, MACF0000017_019, enclosed)?*

I have no recollection of this decision being taken.

152. *Did the Trust consult the Haemophilia Society before it accepted further funding in consequence of the HIV litigation settlement, in accordance with its resolution at its meeting on 20 November 1989?*

Again, I have no recollection of this meeting.

153. *Do you consider (from your perspective as a Trustee) that the Macfarlane Trust was well run? Do you consider that it achieved its purposes?*

Were there difficulties or shortcomings in the way in which the Macfarlane Trust operated or in its dealings with beneficiaries and applicants for assistance?

Yes. The Trust was well run given the paucity of resources available to it. I do not consider that it achieved its purposes, hence the ongoing actions regarding recompense/compensation. I have covered these in additional material later.

154. *Have you had any involvement with any of the trusts or funds apart from the Macfarlane Trust? If so, please provide details of your involvement, role and responsibilities including:*

No.

154(a) *Any involvement you had in relation to the development of any criteria or policies relating to eligibility for financial assistance;*

154(b) *any involvement you had in providing advice;*

154(c) *Any involvement you had in assessing applications.*

Only as regards advice with regard to employment.

Section 13: Haemophilia Society

155. *Please provide details of your involvement with the Haemophilia Society. In particular please provide details of your role, functions and responsibilities as a medical adviser to the Haemophilia Society.*

I have had an intimate and welcome role with the Haemophilia Society throughout most of my working life. Initially I was on the medical Board giving advice to the Society. I received a gold medal from the Society for my involvement with haemophilia (see later Appendix).

156. *Please provide details of the AIDS conference in Newcastle which you organised, with David Watters of the Haemophilia Society, in 1986 (copy programme attached). What was the purpose of the conference? At whom was it aimed? Is it correct that a large trade show, attended by pharmaceutical companies, was held at the same time at the conference centre?*

Please see Exhibit WITN0841029. It is not correct that there was a "large" trade show. From memory, pharmaceutical companies were involved in an exhibition but this was organised by our BTS/Haematology Department members and not by the Haemophilia Centre staff.

Section 14: Involvement with the World Federation of Hemophilia

157. *Please outline your involvement with the World Federation of Hemophilia ('WFH").*

I have been involved with the World Federation of Hemophilia as a member for many years and was responsible for a number of decisions/documents both for the WFH and WHO. I have appended them at the end of this statement.

158. *What role or influence did the WFH have in relation to:*

158(a) *the treatment and care of haemophiliacs in the United Kingdom?*

Only in as much as its publications were read and acted upon/or not by doctors in the United Kingdom.

158(b) *decision-making in relation to the selection and/or use of blood products in the United Kingdom?*

None.

159. *Did the WFH have a relationship with any of the pharmaceutical companies providing blood products to the UK? If so, what was the nature of that relationship?*

Please see Exhibit WITN0841030 my working copy of the WFH Decade Plan.

I have already said that I was instrumental in drawing up a conflict of interest reference for WFH. To my knowledge there was no relationship with any pharmaceutical company providing blood products to the UK other than funding of an impersonal nature. When I was Chair of Funding I managed to reduce the involvement of WFH with pharmaceutical companies, specifically with the help of the now Patron of WFH, and the authoress, Catherine Cookson, who gave me £100,000 for WFH.

160. *What, if anything, did the WFH do in response to the risks arising from the use of blood products in the UK?*

WFH regularly published advice with regard to risks specifically in conjunction with the Centers for Disease Control; Dr Bruce Evatt from CDC was another Executive member of WFH.

Section 15: Other issues

161. *In 1983, following the publication in The Mail On Sunday of an article by Susan Douglas, you made a complaint to the Press Council about the article? Why?*

Because it was alarmist. If the Inquiry wishes I can provide two files on actions of the Mail on Sunday, which revealed the truth behind that publication and subsequent complaint to the Press Council.

162. *In 'The Reunion' (transcript, p. 43) you stated that at the height of the AIDS crisis you used to take between forty and fifty phone calls a night from newspapers. Over what period did this take place? What newspapers contacted you and why? What information did you provide to them?*

That is true, it took place over a short period of time when hysteria about AIDS was at its height. Media outlets including newspapers from around the world rang in. I provided them with up to date factual information about AIDS to the best of my ability.

163. *In 'The Reunion' (transcript, p. 61) you did not accept the criticism of doctors that was expressed by other participants in the discussion. Is that still your view? If so, why? If not, how has your view changed?*

164. *In 'The Reunion' (transcript, p. 64) you describe the Archer Inquiry as "useless". Please explain the reasons for your opinion. You also claimed-that "I know from experience that some people who gave evidence at that inquiry lied". Please provide details of the lies which you claim were told at the Archer Inquiry.*

165. *You further describe some members of the haemophilia community as "so angry" (p. 64). You state that the anger "should be dissipated by now", that they "want money" and are "doing harm not only to themselves ... but also to the new generation of people-with haemophilia". Are these still your views? If so, why?*

Answers to 164/165/166:

These questions all relate to the radio programme, The Reunion, on which I had been invited to comment a few days before. I agreed to join the programme on condition that another party would not be invited because of her bias and adverse comments for many years in relation to the Newcastle Centre and its staff. This was agreed with the producer but, unknown to me another participate, Colette Wintle, was actively working with the other party. As a result, her attitude and answers were strongly biased, not factually based and difficult to deal with whilst on air.

In particular, I do not accept the criticism of doctors especially with regard to the counselling of patients and their families and to informed consent. I do believe that the anger, which is a normal part of the grieving process, should have reduced over time and that the continued campaigning using false information can only do harm to the new generation of patients and their families. My record shows that I was an active campaigner for compensation myself (see appended documents) and I therefore suggest that I do know what I am talking about. As to the question relating to lies, the medical record involved contains evidence of these but is of course confidential.

With regard to the Archer Inquiry, I stand by my comment for the reasons stated in the transcript. My colleagues and I were informed at an early stage that it was a "fishing exploration", which is why we did not participate. In addition, there was no information on funding.

166. *Please provide details of any complaints made about you (insofar as relevant to the Inquiry's Terms of Reference) to your employer, to the General Medical Council, to the Health Service Ombudsman or to any other body or organisation which has a responsibility to investigate complaints.*

Any complaint made about me has been through the General Medical Council. Letters of the outcome of these complaints are at Exhibit WITN0841031. Included are the letters of reference in my support during the prolonged GMC litigation and giving the outcome of the GMC litigation and its response. Please note that the names of patients are included in this response.

167. *Please explain, in as much detail as you are able to, any other issues that you believe may be of relevance to the Infected Blood Inquiry.*

Please find appended WITN0841032 further details of my involvement with the Haemophilia Society/compensation/haemophilia care.

Addendum

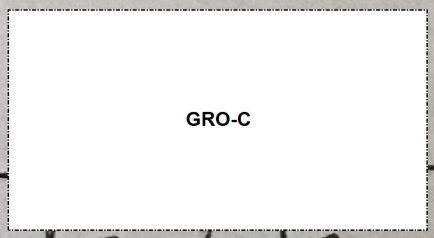
1. *This Is Urgent booklet, 1987, (Exhibit WITN0841033) prepared in association with the Haemophilia Society for Members of Parliament. This campaign eventually led to the 10 million pounds government grant for the Macfarlane Trust. Accompanying the booklet is an article from The Times, November 6th 1987, also articles to The Times on the need for financial help.*

2. *WFH/WHO documents on haemophilia which I edited (Exhibit WITN0841034).*

3. *Report on community support centre which was initiated in part by the Centre staff and includes letters to Social Services Committee of the House of Commons and a reply to a letter to the Prime Minister in 1987 (Exhibit WITN0841035).*

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed 

Dated: Sept 17 2020