Witness Name: Maureen Fearns
Statement No.: WITN404201
Exhibits: None
Dated: 23/7/20

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MAUREEN FEARNS

I, Maureen Fearns, will say as follows: -

1. My date of birth is GRO-C 1945. I qualified as a state registered nurse (SRN) in March 1967.

My career

2. Between 1967 and 1969, I worked as a staff nurse on a medical ward at Royal Victoria Infirmary, Newcastle (RVI). In 1969, I was promoted to sister on the same ward, and was relief-sister for other wards. In 1973, I was selected for the job of sister on the proposed new haemophilia centre (the centre). The centre did not open until several months after my appointment. In the meantime, I gained relevant experience, working as a sister on the fracture clinic, and on the paediatric ward.

3. In 1974, the centre opened. I worked there until my retirement. I was promoted to senior nurse, around 1983. My job title was changed to clinical nurse specialist (CNS) in about 1987.

4. In 1991. I was awarded the haemophilia society vellum '*in gratitude for her devoted care of people with haemophilia in the Newcastle area and for her professional skill as a clinical nurse specialist which has been recognised internationally by the World Federation of Haemophilia and National Member organisations*.'

5. I retired from my job in March 2003. After my retirement, between June 2003 and June 2004, I worked for a year part-time in the community haemophilia service, teaching families how to do home therapy and follow-up.

Membership of associations and working parties

6. In 1982, together with Trish Turk (a nurse from Lord Mayor Treloar College) I founded the Haemophilia Nurses' Association (HNA). I was the chair of the association for about the first 8 years, and remained a member until my retirement.

7. In the late 70s, I joined the nursing committee of the World Federation of Haemophilia (WFH). Christina Brachmann, from the Bonn Haemophilia Centre in West Germany, was the chair. We met about three times a year initially, in order to develop an illustrated haemophilia guide for developing countries. After the guide was published, we met alternate years at WFH

meetings. I became the chair when Christina Brackmann stepped down in 1985. I remained the chair until 1995.

8. In 1976, I was a member of a home therapy working party for the Haemophilia Centre Directors' Organisation (HCDO). Between 1974 and 1978, I was a member of the World Federation of Haemophilia Home Therapy Committee.

9. Between 1989 and 1990, I was a member of the Aidset working party, advising the English National Board for Nursing (ENB) on the contents of 'ENB 280', a training course for nurses on HIV and AIDS.

10. Between 2000 and 2003, I was a member of the Advisory Boards of the Global Nurses' Meeting and the European Nurses' Group, advising these bodies on the programme content for Haemophilia and related bleeding disorders.

11. I have never provided any evidence or been involved in any other inquiries, investigations, criminal or civil litigation in relation to 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.

The haemophilia centre at the Royal Victoria Infirmary, Newcastle

12. I started working at the centre when it opened in 1974. To start with, there was only the consultant and his secretary, a physiotherapist, a social worker and me. Gradually, the staff team expanded.

13. We were an outpatient centre, but had access to 2 haematology inpatient wards, one for adults and one for children. Patients with haemophilia who needed admission to hospital for any reason (e.g. surgery) would usually be admitted to these wards. We would attend them on the wards, to provide care for their haemophilia.

My responsibilities

14. I was the manager of the nursing staff, and was responsible for co-ordinating the clinical work at the centre on a day-to-day basis. I also had the following responsibilities (not an exclusive list):

- administering prescribed treatments at the centre;
- providing general support to patients at the centre;
- teaching patients, parents and other carers about home treatment—e.g. how to recognise bleeds, how to store and administer the treatment, how to record the treatment;
- doing home visits, after diagnosis and after home therapy;
- doing school visits, educating the teachers about how to facilitate the management of the child's haemophilia at school, so as to minimise disruption to the child's education;
- attending patient groups as necessary, including parents' groups and bereavement groups.

Other staff

15. Dr Jones was the consultant and the director of the centre. In about 1978, Dr Hamilton was appointed as co-director with Dr Jones. Dr Jones retired in 2000. He was eventually replaced by Dr Hanley. Dr Hamilton retired about a year before me, probably about 2002, and was replaced by Dr Kate Talks.

16. The haematology registrars and senior house officers would work in the department from time to time.

17. At first, I was the only nurse at the centre. In about 1976, another nurse was appointed, Staff Nurse Jean Bell. More nurses were appointed in the 1980s. I cannot remember the names of all the nurses that worked at the centre at different times. My deputy from about 1984 was Senior Staff Nurse Julie Vowles; staff nurses at different times were Lesley Basey and Alex Whittle.

18. Soon after the centre opened, we had a psychologist and a psychiatrist attached to the team. The psychologist, was Peter Britten; the psychiatrist was Desmond Dunleavy.

19. Our physiotherapist was Brenda Buzzard. Our social workers at different times were Bill Morgan, Jean Lovey, Pat Latimer and Jeannie Frazer.

20. Dr Jones arranged for named orthopaedic surgeons, general surgeons and dental surgeons to treat our patients when necessary. The orthopaedic surgeon was first David Stainsby, later Roger Hornby. The paediatric dentist was René Porteous, and later Professor Steele. The adult dentists were Mr Geffner and Mr Murgatroyd. The general surgeon was Brian Fleming.

21. We had a weekly multi-disciplinary meeting chaired by the director. This involved updates, exchange of information and planning.

Decisions as to the selection and purchase of blood products

22. I think that the hospital pharmacy dealt with the contracts for purchasing blood products. The pharmacists that I remember were Ron Elder and Audrey Saunders. There were occasional meetings between doctors and pharmacists about the ordering of blood products. Initially the centre was part of the trauma unit then changed to be part of the cancer centre; sometimes the unit manager would be present at these meetings.

23. These meetings would decide which products to purchase from which companies. When new products came along (e.g. heat-treated blood products) then Dr Jones would immediately put in an application for funds to purchase these. Funding applications needed to be approved by Barry Dowdeswell. (I cannot remember his job title.)

24. During my time at the centre, I think I probably went to 1 or 2 of these meetings. I was not qualified to express an opinion on the medical advantages and disadvantages, but could advise about ease-of-use and the kits provided with the concentrates. If any problems had occurred, e.g. if one of our patients had had a reaction to a particular product, I could feed this back to the meeting.

Decisions as to the use of blood products (including factor VIII and IX concentrates) for patients' treatment

25. The doctors would prescribe treatment from the products purchased. Only the doctors had the authority to prescribe.

Decisions as to what information to provide to patients about treatment, testing and/or diagnosis

26. So far as I am aware, there was never a 'decision' about what information to provide to patients. We would ensure that whatever information was available to us was also available to the patients and carers.

27. The doctor would have a lengthy consultation with the patient and/or parent before the initial treatment or any new treatment, and would inform them of the benefits and known risks of the proposed treatment. Nurses would often be asked to repeat some of the information later.

28. We had information boards on the wall at the entrance of the centre and in the waiting area, with the latest information about treatments and problems. The haemophilia society had use of a board to post their own notices. We had 2 large bookcases full of literature about haemophilia. Patients could borrow books, and were sometimes given books.

29. Every blood product had a patient information leaflet, with information about the product, its therapeutic effect, known risks, possible side-effects and

reactions. Patients on home therapy, for example, would see this every time they opened the packaging on a product. Nurses would refer to this leaflet and other literature as necessary when answering the patients' questions.

30. Every patient and family diagnosed with a bleeding disorder, was given a leaflet to join the national Haemophilia Society, which was free, and given the contact for the local group. Most patients chose to join the society. We had annual weekend seminars for patients having regular treatment and their families. We usually asked patients beforehand what they wanted in their workshops, so that we could obtain guest speakers on these topics. These seminars were well attended.

31. On joining the haemophilia society, patients and families were also given a book by Dr Jones, called *Living with haemophilila*. There were several editions of this book; each edition would be updated with the most recently available information.

32. When a blood test was carried out for the first time, the doctors would explain the purpose of the test. Nurses would check that the patient understood the purpose of the test when taking the blood. The doctor would explain any abnormal test results to the patient. Again, the nurses would repeat the information later as necessary. Any information available to us was passed on to the patients.

Treatment and testing of patients

33. In 1974, when I started at the centre, we obtained blood products from the Bio Products Laboratory (BPL). Most of our adult patients were treated with cryoprecipitate. This was usually given as an inpatient or an outpatient treatment; it was unsuitable for treatment at home.

34. At that time, there were limited supplies of factor-concentrates available from BPL. Those available were given to children. Up to the age of about 6, children were normally treated with cryoprecipitate. They would go onto concentrate from about age 6, in preparation for home therapy.

35. As time went on, more factor-concentrates became available. These were mainly manufactured by commercial companies from international blood donations. I recall that products were retested somewhere in the UK before being released for sale. I don't recall where this was or what the tests were.

36. More patients were then treated with factor-concentrates. They were seen as a breakthrough, because the patients could take them to school or work. They could treat themselves immediately when there was a bleed, and get on with their lives. At about this time, we stopped using cryoprecipitate for the routine treatment of haemophilia.

37. I recall attending a European Haemophilia Meeting in about 1976. Dr David Owen, the Minister of State for Health, addressed the meeting at the end. He promised that the government would provide funding to secure the provision of blood products from UK sources, sufficient to meet the needs of all UK patients. However, this did not happen, ever.

38. Heat-treated products came out in the 80s. Heat treatment was thought to reduce or eliminate the risk of infection, but no one knew. All of the companies did not produce them at first.

39. We obtained these as quickly as we could. The first people to have them were previously untreated patients. As new supplies came in, all our patients were switched over. The first treatment would be given in the centre, so that we could monitor the patient during and after the treatment.

40. Recombinant products became available not long before I retired. When funding was made available, I recall changing patients over to recombinant products as quickly as possible.

41. Some mild and moderate haemophiliacs could be treated with desmopressin, rather than with blood products.

Home and prophylactic treatments

42. Once sufficient factor-concentrates were available, we started a home treatment programme. Everyone who wanted and could cope with home treatment was offered home treatment, adults and children alike.

43. The consultant would meet with the patient, parent or carer, and discuss everything to do with home therapy. A nurse would usually be present for this discussion. It was up to the patient or parent if we went ahead.

44. If the decision was to go ahead, a nurse would take over, training the patient or carer how to detect a bleed; how to reconstitute and administer the treatment; how often and how much; how to record the treatment; when to contact the centre. They were given a booklet, the *Home Treatment Handbook*. I would go through the booklet in person with the patient or carer. Items such as a fridge were purchased if needed, and a home visit was made to assess progress, evaluate problems and give support. The visits would be carried out by nurse and/or social worker.

45. If a patient needed to treat himself 3 times in any one week, we would ask if he would like to try prophylaxis, to prevent bleeds. Where appropriate, the patient would switch to prophylactic treatment, 2 or 3 times a week.

46. All adult patients had a haemophilia review at least once a year; all children at least 6-monthly. Some patients required more frequent follow up, e.g. Those

on prophylaxis. They would have a physical examination and routine blood tests.

Blood testing

47. The routine blood tests were full blood count (FBC), liver function tests (LFTs), urea and electrolytes (U+Es), factor level, inhibitor screen, and a hepatitis B antibody test.

48. At least once a year, our patients would have their treatment in the centre, stay for 3 hours, and have blood tests to monitor the response to treatment.

49. Dr Hamilton, the co-director of the centre, had previously worked in a liver unit. From 1979, he held a liver clinic at the centre. Patients with abnormal LFT results would be reviewed at this clinic. Dr Hamilton would refer some patients to Dr Record, a hepatologist.

50. When tests for HIV and hepatitis C became available, we offered these to all our patients, as set out below.

Consent to treatment and blood testing

51. A doctor would have a lengthy consultation with the patient and/or parent before the initial treatment or any new treatment, and would inform them of the known benefits, side effects and risks of the proposed treatment. The doctor would sometimes draw diagrams, to show how the treatment worked. Available precautions were discussed, e.g. vaccinations against hepatitis A and B. When heat-treated blood products (and, later, recombinant products) became available, the potential advantages of these were discussed. The patient and/or parent would decide whether to accept the treatment or not.

52. For patients with mild or moderate haemophilia, treatment with desmopressin was discussed, as an alternative to blood products. Desmopressin was not

clinically effective for severe haemophiliacs. Often, but not always, it was effective in the treatment of patients with mild or moderate haemophilia.

53. Regarding risks, the doctors could only discuss the risks that were known at the time. See under 'knowledge of risk', below

54. The first time the routine blood tests were taken, the doctor would explain the tests and their purpose to the patient and/or parent. If the blood results were normal, they would be discussed at next appointment; if the blood results were abnormal, the patient would be called in earlier. Most of the patients had a very good understanding of their condition, including the blood tests. Their knowledge would be re-enforced every time we had a discussion about the latest blood tests.

55. Before taking a test for HIV or hepatitis, the patient would have a meeting with the doctor, at which a nurse would normally be present. The doctor would give the patient full information about the purpose of the blood test, and the possible significance of the results. This included information about the possible social consequences of a positive result, for example, the effect on mortgages, insurance and travel. I could re-enforce this information as necessary before taking the blood. There were information leaflets and other literature around the centre about HIV and hepatitis. Everything we knew, we would tell the patient.

56. I have been asked, 'To what extent were decisions about treatment and testing taken by the doctors rather than the patients?' As is usual in clinical practice, the doctors used their clinical knowledge to decide which of the available treatments and tests might benefit the patients, and would explain and offer these to the patient. The patient would make a free decision of what treatments and tests to accept.

57. So far as I remember, we did not use consent forms for haemophilia treatments at any time. I remember that consent forms were used for treatment with AZT (for HIV or AIDS) and for treatment with interferon (for hepatitis C).

58. I was not a nurse-prescriber and was not trained in the process of obtaining consent. Consent was always obtained by the doctor.

59. Patients would often ask me questions about treatment and testing. I would answer these to the best of my ability, and consult the literature as necessary. I have been asked whether I was ever told to withhold information from a patient or patients about risks, or treatment, or testing, or diagnosis, or their condition. The answer is no, never.

60. So far as I remember, the approach to obtaining consent to treatment did not change over time.

Policies and standard operating procedures

61. I do not remember what policies were in place. They would have reflected the HCDO guidelines in place at the relevant time. At all times, our doctors treated and tested the patients in accordance with the relevant HCDO guidelines.

62. I have been asked about 'standard operating procedures' at the centre. I do not remember the words 'standard operating procedure' ever being used about haemophilia treatments.

Knowledge of risk

63. When I started at the centre, I was aware that there was a risk of transmission of hepatitis A and B through blood products. We would test patients for

immunity, and offer a vaccination before starting treatment if they did not have immunity.

64. I think that there was a vaccination for hepatitis A available when I started at the centre. As soon as a vaccination for hepatitis B became available, we offered this to all our patients who were not immune.

65. My understanding was that there was a significant risk of hepatitis B to patients who were not immune, until we were able to vaccinate them; after this, there was very little risk. So far as I remember, none of our patients needed treatment for liver disease as a consequence of hepatitis B.

66. We first became aware of hepatitis C in the late 70s. There were many cases of abnormal LFTs; we realised that something other than Hepatitis A or B must be causing these. For a time, we thought that the LFTs were raised because the patients required a lot of replacement therapy to treat or prevent bleeds, not because of anything wrong with the product. At first, we did not think that this was life-threatening. Later, we realised that there was another virus causing liver problems; we called this 'non-A non-B'. Members of staff went to meetings and seminars; gradually, we found out more about it. Whatever information came into the centre was disseminated by the director to all members of the team.

67. I first became aware of HIV (then known as 'HTLV3') in about 1983, at a meeting. I do not remember for sure, but think it was a meeting of the World Federation of Haemophilia in Sweden or Rio. We were told that there were concerns that a small group of haemophiliacs in America had become ill through blood products. I think that the source of the information was the Centre for Disease Control in the USA.

68. Gradually more information became available. We read the literature and held meetings and seminars at the centre. We would attend meetings and

seminars in other centres, and would disseminate the information to other staff when we came back.

69. In order to reduce the risk of infection, we switched over to heat-treated products, as soon as these became available. We also used desmopressin where clinically indicated.

70. When a test for HIV became available in 1984 or 5, we offered this test to our patients and their partners. The results were a terrible shock. We had about 130 patients with severe haemophilia; about 90 of these were positive for HIV. A few patients with moderate haemophilia were also positive. About 6 of the patients' wives or partners were positive; I do not remember the exact numbers.

71. Tests for hepatitis C became available in the 1990s. We offered tests to all our patients. This revealed that a number of our patients had hepatitis C. Some patients were positive for both HIV and hepatitis C.

72. I do not remember any specific training or advice about informing patients of the risks of infection. As a matter of course, when information became available to us, we made this information available to the patients. This was mostly verbal, but there were also leaflets, because the haemophilia society and many companies produced leaflets. There was also information on our information boards.

Commercial and NHS blood products

73. When we first started using the commercial products, we did not know that the risks of infection were greater with commercial products than with NHS products.

74. The information leaflet in the box would state the size of the pool (i.e. how many blood donations had been used in the manufacture of the product). The pool was much larger for the commercial products than for the BPL products. This was just one piece of information among the large amount of information available about each product. I later realised, in hindsight, that this increased the risk of infection. I had not made the link between the size of the pool and infection risk until then.

Care of infected patients

75. I do not remember any new positive results for hepatitis B at the centre. Sadly, we had many positive results for hepatitis C and HIV.

76. We arranged special clinics to give patients the results of blood tests. When patients tested positive for HIV or hepatitis C, they would be called in to the next clinic. There were no delays in communicating the test results, unless there was a missed appointment or, for example, if the patient was abroad.

77. The doctors would discuss the test results with the patient, and answer all the patient's questions. Patients had the chance to digest the information and to ask more questions. We ensured that there was sufficient time for this; there were only 2 or 3 appointments in a morning for these clinics.

78. It was always a doctor who communicated the test results to the patient, though a nurse would usually be present. The social worker would attend these clinics to provide support.

79. Patients usually informed their partners if they tested positive. We offered tests to family members of infected patients. About 6 of these were positive.

80. Whether the test results were positive or negative, many patients wanted to discuss alternatives to treatment with blood products. By this time, I think all our patients were on heat-treated blood products, which were thought to carry

little or no risk. However, some patients chose to stop prophylactic treatment at this time; some patients decided to stop all treatment. Most of these patients started again later, when they realised how bad were the effects of untreated haemophilia.

81. The infections affected our patients' mental and physical wellbeing. Patients became very ill, and suffered side effects from the treatment. Many patients also were frightened and depressed.

82. With HIV, patients were frightened to talk to anyone outside the centre about their condition. I remember a patient comparing himself to someone with leukaemia. 'It is a terrible condition, but when he gets home, he can tell his parents and friends. I can't open my mouth when I leave this department.' With hepatitis C, there was less need for secrecy, but patients were still frightened of the stigma.

83. There were no established treatments for HIV or hepatitis C. Our own consultants worked with infectious disease consultants, Dr Snow and Dr Ong, in providing care. Patients with HIV were given the opportunity to participate in a clinical trial of AZT at the centre. They were told that they could withdraw from the trial at any time, and this would not prejudice their right to participate in any future trials.

84. Patients with hepatitis C were treated by Dr Hamilton and Dr Record. Dr Record and his clinical nurse specialist ran a trial of treatment with interferon.

85. I personally did not administer treatments for HIV or hepatitis, though I always knew what was happening with our patients. If patients needed inpatient treatment for their infections, they were either treated on our haematological wards, or on the infectious diseases wards at Newcastle General Hospital. Staff from the centre would go to the wards to administer the haemophilia treatments. Ward staff would provide treatment for the infection.

86. Patients taking AZT would suffer nausea and fatigue. Interferon was given to patients with hepatitis C. Interferon caused terrible side-effects for some patients; they had difficulty eating, drinking and sleeping, and lost a lot of weight. These were some but not all of the side effects.

87. Many of the patients with HIV died. There were also some, though very few, deaths from hepatitis C.

88. As time went on, better treatments were developed for HIV. These controlled the disease much more effectively, and rarely had side-effects. Patients with hepatitis C were still having interferon at the time of my retirement, but better treatments came after I retired.

89. We would provide infected patients and their families with advice about how to avoid infecting others. The social workers and I did a weekend seminar for the carers to go over all the issues on hygiene and prevention of infections. I do not remember exactly what advice we gave at different times. These were similar to the universal precautions taken by healthcare staff when administering treatment. We issued condoms and disposable gloves.

90. The patient's GP was informed of the diagnosis, with the patient's permission, after discussion with the patient. If infected patients needed surgery or treatment for other medical conditions, the clinical staff treating them were made aware of their infected status. They had to in order to do their jobs. This information was kept strictly confidential.

91. Initially, we advised our patients not to conceive, because this could infect both mother and baby. Later, when treatments advanced, this advice changed. Partners of our patients did have babies, while I was working at the centre.

92. Social work support, including home visits, was provided by our social workers. I believe that social work support was also available from 'regional co-ordinators for HIV'. The social workers set up the 'Ushaw Project'. Student priests from Ushaw College in Durham were available to befriend patients and/or their families, if they wished. The student priest was someone that the patient could talk to outside the centre and outside his family.

93. We had a psychologist, who could provide counselling. I did a counselling course, and sometimes provided counselling myself. Our patients and their partners could receive support from whomever they felt most comfortable with.

94. I have been asked whether infected patients were treated differently to other patients. Staff caring for infected patients would take precautions in accordance with the policies of the hospital. For example, infected patients having surgery would be placed at the end of the list. However, it would be wrong to say that we treated infected patients differently; as with all patients, we treated them according to their clinical needs.

Research

95. I do not remember any research into haemophilia treatments taking place at the centre.

96. We held a trial of AZT for HIV positive patients, and a trial of interferon for patients with hepatitis C. Dr Jones was leading the AZT trial. I think Dr Hamilton and Dr Record were leading the interferon trial; Dr Jones had been involved at earlier stage as he was instrumental in obtaining the funding for hepatitis C treatment. Dr Record had his own research nurse, to assist.

97. I had limited involvement in these trials. I remember teaching patients how to give themselves their interferon injections, and talking with the patients about the side effects. I cannot remember details.

98. All patients involved in research were fully aware of the research. There were consent forms for participating in the trials. A doctor would go through the consent form with the patient. If willing to participate in the trial, the patient would sign the form.

99. In this context, I have been asked about use of the acronym 'PUPS', meaning 'previously untreated patients'. We used this term to refer to haemophiliac patients (usually children) who have not previously been treated for their haemophilia. This meant that a long appointment was necessary, to discuss treatment options before commencing treatment. To the best of my memory, none of the research trials at the centre involved previously untreated patients.

Variant CJD (vCJD)

100. I first became aware of vCJD in 1997. We had a letter from BPL, with a list of batch numbers of British concentrate which had included the blood of an infected person. The letter also said that there was no test or treatment for the condition. Not long afterwards, we had a letter from the Department of Health (DOH) and Lothian Ethics Committee. This instructed us not to tell the patients who had had blood products from the infected batches, since there was no test or treatment.

101. I was outraged at this letter. It was completely against the principles of our centre. I wrote a letter to the haemophilia society, protesting at the instruction not to tell patients. Dr Jones was away from work at that time; Dr Hamilton dealt with the situation. Like me, Dr Hamilton was not happy with the instruction from the DOH. I understand that he took it up with the medical director of the trust, Dr Brewis.

102. Not long afterwards, we had another letter which listed more batch numbers. I think that this letter also came from the BPL, but I am not sure of this.

103. To the best of my memory, the haemophilia society then sent a letter to all patients prescribed factor-concentrates, explaining that batch numbers had been identified, and that there was no test or treatment.

104. At that time, we discussed the information with all our patients. We would say, 'We have a list of batches. Do you want to know whether or not you/your child ever received treatment from any of these batches?' We said that there was no test and no treatment. All information available to us was passed on to the patients, according to their wishes. Some patients did want to know; others did not.

105. This news naturally caused anxiety to our patients and their families. The medical and nursing staff spent time talking to the patients and the relatives, as did the social workers. The social workers would do home visits. The psychologist was available to provide counselling. The patients and families could talk with the person they felt most comfortable talking with, nurse, social worker or psychologist.

106. Fortunately, while I was at the centre, none of our patients became ill with vCJD.

Effect on clinical staff

107. Staff followed hospital policies for the prevention of infection. The policies changed over time. At the beginning, there were special precautions for infected patients; later, the precautions became universal, for all patients in the hospital, not only those known to be infected.

108. I do not think that there was a formal 'whistle-blowing' policy at the trust before my retirement. Staff who had concerns about staff or patient safety

could raise this with their line managers. If the concern was about the conduct of the line manager, they could go to the next one up.

109. I did raise one major concern during my time at the centre. This was about the DOH letter about vCJD, as set out above. I raised this concern with the haemophilia society.

Impact on me

110. I have been asked, *What impact did treating haemophilia patients who subsequently contracted infections from their treatment have on you, both personally and professionally?* I will need to answer this at some length.

111. I had been thrilled to be offered the post of haemophilia sister on a unit which was yet to be established. The first years after setting up the unit was spent learning on the job as this was relatively new post. It was exciting and challenging. There were many inpatients at first, but these decreased as we taught patients and families how to give their own treatments at home with the newly available factor-concentrates. It was wonderful to observe the difference in life for children and adults who could then gain some independence from hospital. This enabled the children to go to school and adults to pursue a career. Early treatment reduced pain and destruction of joints.

112. When the viruses, especially HIV, were found in the haemophilia population, it was total devastation for them and their healthcare providers. I recall my feelings of guilt having given the treatment—irrational as I had no knowledge of the viruses' presence—and feelings of anger, disbelief and inadequacy.

113. I realised very quickly that I would need to source information which would give me the necessary skills to continue to care for my patients and their

families. I was encouraged and enabled to attend courses, seminars and meetings which would help me gain these skills.

114. As people became ill, it became more difficult to deal with the physical and emotional issues for them and myself. I could not walk away. I wanted to do the best I could to help treat and support them.

115. There were many sleepless nights, nightmares and tears. Friends and family continuously worried about my personal safety and well-being. I recall not been able to switch off when I got home from work. At the end of a bad day, I was unable to discuss things with my husband or friends because of confidentiality. I think there was some resentment that work was taking over my life and that I had little time left for my family.

116. I often returned to work during the night to sit with the family of a dying patient. Often it was parents with their child whom I'd known from birth. We never seemed to have time to recover before the next family needed help. It was extremely distressing. The clergy were wonderful. They sat with families if they so wished, and also spent time talking us through what had happened.

117. We felt it was part of our role to attend patient funerals. Two members of the team would go. The families were pleased to have representation from the centre. We were grateful for the opportunity to say goodbye. Sometimes I would be asked to give the eulogy. Sometimes we could not introduce ourselves to other mourners, who had not been told about the haemophilia due to fears that they would find out about the virus.

118. We set up groups, weekend seminars and evening meetings for patients and families, and bereavement groups. The extra work often left me so physically and emotionally tired that I did not want to go to work, but I did, just as every other team-member did. I know I was not the only person in the team who experienced some or all of these feelings

119. I was so glad that the HNA was there so that we nurses could all share our feelings and fears and support and learn from each other. In Newcastle, we were a solid team so every member supported each other. The hospital priest and chaplain were wonderful; they were there for us and for families.

120. I would like to add that providing this statement has brought back feelings I thought I had left behind after 17 years of retirement. I feel for the patients having to relive this.

Other Issues

The Haemophilia Nurses' Association

121. When I started work at the centre, there were no courses for nurses about haemophilia, and no forums for haemophilia nurses. In about 1976, pharmaceutical companies provided funding for meetings of haemophilia nurses. At the time, were only about 10 to 20 Haemophilia centres who had Haemophilia nurses. We had occasional meetings, and would exchange information about how we cared for patients in our areas.

122. In 1982, Trish Turk and I decided to get it on a more formal footing, and set up the HNA. I was the chair of the HNA for around 8 years. The position was taken by Alex Shaw (now deceased) from Manchester children's hospital.

123. We had national meetings every 12 to 16 months. We arranged for nurses to go from one centre to another centre for a learning experience. As the number of haemophilia nurses increased, we set up regional groups and would hold regional meetings about twice a year.

124. At our meetings, we would exchange information and best practice, and would invite guest speakers. We sent out an annual newsletter, and had a booklet printed with names and addresses of nurses, social workers and

physiotherapists specialising in haemophilia, so that we could ring each other and discuss issues, or ask for advice.

125. We had representation at the Haemophilia Society meetings, and were eventually allowed to attend HCDO meetings. We were allowed to have input with BPL to discuss the contents of the home treatment pack and literature to give to patients. After a few years, the HNA was affiliated to the Royal College of Nursing (RCN).

The article on Haemnet in 2019

126. I have been asked about an article on www.haemnet.com titled 'contaminated blood—lessons for our future', published in 2019.

127. I did not write this article, and had not seen it until the Inquiry sent me a copy this year.

128. Last year, the HNA invited Christine Harrington and me to give a presentation about haemophilia nursing in the 1970s and 80s, when so many patients were infected from blood products. Our presentation was put at the end of the programme. Other items overran so little time was left. We spoke for a few minutes only.

129. The article on Haemnet appears to be a report of our presentation. It was written without my knowledge. I have no objection, but would have appreciated being shown a copy before publication, since I could have corrected errors.

130. The article states that I said that '90% of our patients were positive'. I did not say this, and it is incorrect. We had about 600 patients, of which about 130 had severe haemophilia. Of these, about 90 were HIV positive. I think that

about 4 or 6 patients with moderate haemophilia were HIV positive. 6 of the partners of our patients were HIV positive.

Financial support

131. The Macfarlane Trust, the Skipton Fund and the Caxton Foundation existed to provide financial support to infected patients with haemophilia. Dr Jones was involved in setting up the first of these. We were aware of these funds and would invite our patients to speak to the social worker if they wished to apply for support to these funds. I had no personal involvement with these funds. I did not need to since the social worker took responsibility.

Records

132. We kept our patients' medical and nursing records in the centre, separately from the hospital record system, so that we had quick access to them at all times. When a patient moved to another area or died, the records went into hospital record system and were archived.

133. In addition to the medical and nursing records, there were treatment record cards for all our patients, with information about each treatment.

On the front of the card:

- Name
- Date, time
- Site of bleed
- First treatment or repeat treatment
- Any treatment other than the concentrate

On the reverse side:

- Name of product
- Batch number
- Number of units
- Expiry date of batch

- Comments

134. The same treatment card was used for home treatments, treatments in the centre, and treatments on inpatients wards. The patient or carer would fill it in at home; the nurse in the centre or on the wards. The cards were kept separately from the medical and nursing records.

135. We collated some of the information from these cards each year on a graph, showing the frequency of bleeds and the sites. The graph would be discussed with the patient at the end of each year, and then filed in the medical notes.

136. We had many thousands of treatment cards going back many years. We filed these in a room at the centre, separately from the medical and nursing records. At some time in the late 1990s, many of the older cards were removed from the room. This was organised by Ernie Richardson, directorate manager, and Joan Shield, secretarial manager, without input from the unit-secretary or myself. I think that they were removed to be scanned and stored electronically.

137. The treatment cards were the only records kept apart from the main hospital records.

Conversations with former colleagues

138. I have been asked about any conversations I have had with former colleagues about the issues covered in this statement.

139. As a team, we discussed these issues every day. We also might have discussed, in passing, news or television reports. Since retirement, I have had social contact with former colleagues. We have never met to discuss any

- Comments

134. The same treatment card was used for home treatments, treatments in the centre, and treatments on inpatients wards. The patient or carer would fill it in at home; the nurse in the centre or on the wards. The cards were kept separately from the medical and nursing records.

135. We collated some of the information from these cards each year on a graph, showing the frequency of bleeds and the sites. The graph would be discussed with the patient at the end of each year, and then filed in the medical notes.

136. We had many thousands of treatment cards going back many years. We filed these in a room at the centre, separately from the medical and nursing records. At some time in the late 1990s, many of the older cards were removed from the room. This was organised by Ernie Richardson, directorate manager, and Joan Shield, secretarial manager, without input from the unit-secretary or myself. I think that they were removed to be scanned and stored electronically.

137. The treatment cards were the only records kept apart from the main hospital records.

Conversations with former colleagues

138. I have been asked about any conversations I have had with former colleagues about the issues covered in this statement.

139. As a team, we discussed these issues every day. We also might have discussed, in passing, news or television reports. Since retirement, I have had social contact with former colleagues. We have never met to discuss any

issues related to this. It was dreadful to go though at the time; I have not wished to re-live it.

140. I have not discussed the contents of my statement with any of my former colleagues. My statement is entirely personal.

The contents of this statement are true to the best of my knowledge and belief.

Signed. GRO-C

Dated: 23/7/20