

Witness Name: Jennifer Jones

Statement No.: WITN3621001

Exhibits: Nil

Dated: 29 June 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JENNIFER JONES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7 February 2020.

I, Jennifer Jones, will say as follows: -

Section 1: Introduction

1. My name is Jennifer Jones. My date of birth is GRO-C 1947 and my address is known to the Inquiry. I trained at St Bartholomew's Hospital ('Bart's') in London and qualified as a State Registered Nurse in 1968.
2. I have 41 years of nursing experience. After qualifying as a State Registered Nurse at Bart's in 1968, I stayed on for another year until 1969 and then moved to Bristol to work in midwifery. I didn't enjoy midwifery and went back into general nursing six months later.
3. In 1971 I moved to Cardiff and in 1972 I became a Ward Sister in Haematology and Gastroenterology at the University Hospital of Wales, which we called the Heath. I was there until September 1977.

4. I then had a short service commission for four years in the Army with the rank of Captain.
5. In 1981 I came back to Cardiff and was looking for a job at the Heath. I had enjoyed nursing haemophiliacs during my time on the Haematology Ward and I still knew some of the patients, who said they wanted me as their nurse, so despite the limited facilities at the Haemophilia Centre, I took a job there.
6. A few years later in around 1989 I became recognised as a Clinical Nurse Specialist. I continued to work in this role at the Centre until I retired in 2003.
7. During my time as a Haemophilia Nurse I was a member of the Haemophilia Nurses Association ('HNA'). I believe this started up in the early 1980's and Professor Bloom, who I called Prof, told me about it initially. I got to know Haemophilia Nurses around the country and went on the Committee for a period, but the yearly meetings were in Newcastle and it wasn't really viable for me to continue on the Committee, although I still continued as a member of the HNA .
8. After so long, I cannot recall exactly what we discussed at the Association meetings but it would have included whatever was relevant at the time.
9. I have never provided any evidence or been involved in any other inquiries, investigations or litigation in relation to the subjects discussed in this statement.

Section 2: The Haemophilia Centre at University Hospital Wales ("the Centre")

10. When I started in the Centre in 1981 the unit was confined to one very small room, about 10' by 20'. The unit had no bed facilities, but it had a couch that we could use for treatment, that we could just about get the curtain around

for a bit of privacy. The unit also had a desk and chair, a filing cabinet, a fridge, a treatment table, two comfy chairs, a store cupboard and a sink.

11. The unit was an outpatient facility for haemophiliac patients to attend if they had a problem, or if they needed to collect treatment. If we were lucky they would phone ahead, but they often just turned up. The number of patients who attended daily varied greatly. After so long I am unable to recall how many patients were on the books when I first started.
12. If haemophiliac patients came in as inpatients they would go to the Haematology Ward, if there was a bed available, or to a different Ward if not. I would visit the Ward to treat them and explain their needs to the staff on duty. Occasionally they might also come into Orthopaedics and I would explain the treatment to the nurses there. If there was a problem out of hours they would go to the Haematology Ward.
13. When I first started, my predecessor Mildred Jones had left a couple of weeks prior and the unit had been running for two weeks without a nurse. The cupboards were pretty bare and I recall spending my life going up and down the stairs collecting supplies. Eventually another Haemophilia Nurse came in to help part-time and I was able to get out into the community to conduct home visits, which was part of the remit of my role.
14. I visited homes and did a lot of training with the youngsters to teach them to do their own treatment. The older boys could do their own treatment and so too could the younger boys, if they were sensible. The boys would practice on me (or on their parents if they were willing), and we also taught the parents how to do the treatment. Another part of my role was to visit schools and talk with teachers, as many were quite anxious at the thought of having a haemophiliac at school under their care.
15. I reported to Prof, who was the person with overall responsibility for the Centre. There were other consultants with their own remit within haematology, for example thalassemia and anaemia, but Prof covered coagulation. I would generally see Prof every day, although sometimes he

was away lecturing. I would sometimes sit in on his meetings with patients for diagnosis.

16. The Registrars that covered the unit moved around in four-month rotations within the different departments of haematology. The Centre also employed its first Clinical Assistant on a part-time basis in the 1980's who was there most of the time. I recall it becoming quite cramped with everyone in that little room.
17. Things got very busy and in around 1987 we moved into a proper unit with more space. Some people in the hospital didn't even know we existed until then. We had a waiting room, separate office, treatment and storage room with a fridge. Next to us there was a research lab, Prof's office, a coagulation lab, and then a blood bank further down the corridor. The blood bank was where we kept the cryoprecipitate. Haematology blood testing labs were more or less in the same area as us when I first started at the Centre, but when we moved again in the late 1990's we were in a different part of the hospital.
18. By the late 1980's or early 1990's we had a full-time Clinical Assistant. There were various Clinical Assistants over time and I can't recall their names, although one of them may have been called Sarah. One moved to Canada and another moved to Australia with her husband who was a haematologist. There was also another nurse, Allan Aldridge who started in 1994. When we moved to the proper unit, the clinicians had their own room, the nurses had a desk, and the Clinical Assistant had a desk too.
19. My nursing colleague retired in the early 1990's and Chris Loran came in part-time but with more hours than her predecessor. The Centre later employed another two part-timers on a job-share. This meant I could get out into the community a lot more. I recall there was a stressful period in the early 1990's due to someone leaving and I was left working on my own, however I can't now recall when exactly this was.

20. Staffing levels at the centre did seem to increase over time, I think partly because of the research side of things. There was always research going on and at some point, Alan Aldridge who was by now a staff nurse on the Unit, was looking after some of the trials. There was also someone in charge of paediatrics, and two social workers. In the mid 1990's, I can't be more exact, Peter Collins came in as a Consultant Haematologist. The Centre was known by then as a comprehensive care centre because all aspects of haemophilia care were handled there.
21. In regards to blood products, Prof had overall responsibility for the Centre and would have been the person that decided what treatments were being purchased and how they were being used. When the Clinical Assistant came in part-time in the 1980's she would see patients quite a bit, and the Registrars were also there. They made the decisions on treatment doses.
22. When treating patients, we would always look at the patient's records to check what treatment they had received before. Initially patient notes were kept down the corridor on the Haematology Ward because we didn't have room in the Centre. The Registrar on call would know where to get the notes and we would have the notes of who was coming in that day on hand. We documented what the patient received on flimsies (duplicated forms), and the Clerical Assistant helped with record keeping and inputting treatment details into the computer. There was a booking out system for the patients on home treatment, recording what they received.
23. We would try to keep a patient on the same batch of treatment for as long as possible. That was our practice before we knew anything about the risks of transmission of HIV and Hepatitis. I can't recall what the shelf life of a batch was, but we always got through it before it got to that point.
24. In terms of stock control, orders were initially done through the pharmacy, which knew Prof's orders. I was responsible for getting stores in for Cardiff and would request more stock if we were running low, which seemed to happen a lot of the time. This changed eventually and all products were kept

at the Welsh Blood Transfusion Centre in Llantrisant. The nurses were still responsible for ordering the treatments.

25. I do not know anyone at the Centre now because my former colleague Chris has recently retired. However, I know that the Centre now has a part-time paediatric doctor just for haemophilia.

Section 3: Knowledge of risk

26. The Centre's approach to the use of blood products depended on the severity of the patient's haemophilia. There are three grades of haemophilia – severe, moderate, and mild. On the whole, patients with mild haemophilia wouldn't be given concentrates. For those who required concentrates, those with Haemophilia A would be treated with Factor VIII, and Haemophilia B with Factor IX.

27. I can't recall whether we had sufficient supplies of British Factor IX treatment for our Haemophilia B patients or whether we also used commercial Factor IX. I know that there wasn't sufficient British Factor VIII to treat patients with Haemophilia A. The Centre's policy was to give children the British treatment, and the older patients would receive the commercial treatment. We called the British treatment 'Lister' in order to differentiate it from the commercial treatment. I'm not sure whether there was any requirement at the time to tell patients what they were receiving and I certainly don't recall being advised to explain it.

28. Although the Centre's practice was to give children the British Lister treatment, our patients often also went to other hospitals where it was likely they received other treatments. Patients could also get treatment at the Gwent Newport and Morriston Hospital Swansea. Aside from Morriston Hospital, which had a Haemophilia Nurse called Pam at one stage, these hospitals didn't necessarily have specialised doctors or nurses. If patients presented there they would just be given whatever treatment was in the

fridge. The treatment would be appropriate but it might have been commercial.

29. Initially my colleague and I weren't aware of any appreciable difference between British blood products and commercially supplied blood products.

30. Whenever possible, we encouraged patients to come and see us in Cardiff because we were a comprehensive care unit with more specialised staff and as such could give patients a better overall standard of care. In the early days the Centre's facilities were obviously much more limited, but as time went on we had a dedicated dentist, orthopaedic surgeon, physiotherapist, social workers and counsellors. We evolved into a one-stop-shop providing all of the services that haemophiliacs needed.

31. I can't recall whether there were any occasions where we couldn't get supplies, were running very low or actually ran out. If one of the commercial products ran out there was always another company that could supply it. Some of the American companies I remember receiving products from were Armour and Alpha, and I also remember Immuno which I think was a German company. Immuno did a special Factor VIII inhibitor bypass product as well. There was also a company that did a porcine Factor product, and a product called Hyate. I can only remember the Immuno rep, who I think was called Bob.

32. When I returned to Haematology in 1981 I was pleasantly surprised that a lot of the older patients I had known, and who had spent a lot of time on bed rest, were now getting on with their lives on home treatment. I presume that my predecessor Mildred Jones had taught them how to use it. It then became my role to visit patients at home and teach them how to self-treat.

33. It was definitely recommended by Prof and senior clinicians that patients should treat at home where feasible. The attitude was that it was better to treat at home, as it meant a haemophiliac could treat a problem straight away rather than having to travel into hospital. I know it made life much easier for a family that lived in the GRO-A area, as well as other families that

lived in the more remote areas in the Valleys. I went to their homes to teach them how to use the treatment.

34. I can't really recall any policies or operating procedures in place at the Centre specifically relating to the use of blood products. I recall that my colleague and I wrote out guidelines for patients on home treatment, but I can't remember any official policies at the Centre about home treatment.
35. My colleague and I were very professional people and always followed general nursing policies, for example around washing your hands. Many policies were simple common sense.
36. Before it came out that Hepatitis and HIV could be transmitted by blood products, the idea had never really crossed my mind. As a nurse you grow accustomed to giving patients treatments, and I suppose with any kind of treatment you could think to yourself "where has this come from?". If I had been told or had a suspicion that there were risks then I don't think I would have wanted to give the treatments to the patients.
37. I can't recall specifically when I became aware of the risks of transmission of HIV and Hepatitis through blood products. However, from memory the news about HIV hit in 1982 or 1983. Prof would have been already aware of it when the news hit, and I recall he held meetings for patient's families and anyone else who wanted to attend to explain what was happening.
38. I would say that there was a raising of awareness but no real training as such. We picked up information from sharing ideas at meetings with other Haemophilia Nurses. We also went along to talks on HIV and Hepatitis that were being held in the hospital complex. A couple of them would have been open talks by Prof and I presume the hospital's Infection Control team also delivered talks on the subject.
39. The fact that I might be at risk from handling the treatment was never really explained to me. However, even when I had been working on the Haematology Ward we had known about patients with hepatitis. We knew about the risks, and I was a firm believer in washing my hands. I suppose I

did read up on things, but there wasn't a lot of self-research done before the time of going online.

40. I think the staff in the Centre and the wider Haematology Department were more aware of the risks than other Hospital departments. The Lab in particular needed to be on top of it. We must have been pretty well versed in everything but a lot of doctors and nurses were not. I remember an instance where an A&E nurse brought an HIV-positive haemophiliac patient to us and was carrying his case whilst wearing gloves. I had to ask her gently why she was wearing gloves. I think we were probably a bit more sensible about things.
41. I can't recall receiving any training or information on the advice to be provided to patients about the risks of infection from blood products. Patients themselves were certainly not always aware of the risks of transmission through blood. One time, a patient with Hepatitis came into the Centre and whipped off a dressing and blood went everywhere. We had to close the Centre and clean everything thoroughly.
42. On another occasion, early on when the Centre's facilities were limited, I obtained a needlestick injury from treating an HIV patient because there was no space and I tripped over his foot. I can't recall exactly when this was but I think the patient died in around 1984. There was no treatment at the time so I just had to let my injury bleed and then wait for blood tests. It was a worrying time but you just get on with it.
43. We had an Incident Register at the hospital and I remember I went to town on the incident form about our facilities and how they had caused the needlestick injury. I bumped into the Chief Nurse in the corridor sometime later and she asked how I was and that was the first senior management contact I had received since the incident. Obviously, things changed when we got our bigger unit and had a proper treatment room to treat one or maybe two patients without tripping up on anything.

44. It was suggested by the Infection Control department in the hospital that hospital staff wear gloves, however I think this was quite early on and was universal for all patients regardless of whether they had an infection. All of the nurses wore gloves and most of the doctors wore gloves. I think most of the other Departments also had posters up on the walls about infection control generally, but I don't think we had any wall space where there would have been room for a poster.
45. I can't recall when the Hepatitis B vaccine came out, but I do remember that my colleague and I were two of the first staff in the hospital to be vaccinated. I think it may have been in the early 1980's. From memory, all staff working in similar situations were vaccinated.
46. When the risks of transmission of HIV and Hepatitis through blood products became known, obviously there was a lot of work done on heat treatment. Heat treatment was carried out on the British products as well as the commercial products. The commercial treatments were safe once heat treatment came into being.
47. It was in the 1990's that recombinant treatment came out. I suspect they were looking at recombinant products for a while before that to see if they were effective. I remember the little kids being put on recombinant treatment. Presumably this is what everyone is treated with now.
48. At the time some of our patients started being treated with cryoprecipitate again, as opposed to concentrates. Cryoprecipitate was a plasma product that was made locally by the Blood Transfusion Service and was considered favourable to commercial products in terms of safety. However, because it was a plasma product people still contracted infections through using it. There were no donor screening tests at the time to ensure the plasma was safe.
49. By the time my new colleague Chris Loran started in 1992 and Prof had died the same year, all of the treatments were heat treated and we didn't have any problems that I was aware of.

Section 4: Testing, treatment and care of patients

50. I can't remember whether any information was produced nationally or through the hospital locally, to give to patients about the risks of infection from blood products.

51. When the risks became known, I'm sure that Prof saw all of the patients personally, however I wasn't present for all of these meetings. While I would sometimes sit in on meetings such as genetics for example with Prof, his office was quite small and it would be too cramped if Prof and the patients and their families were all present.

52. I also can't remember what information was provided to patients about alternative treatments, however alternative treatments were available and used where possible. As I have already mentioned, the Centre's policy was that mild haemophiliacs would not be treated with blood products other than in exceptional circumstances.

53. Mild patients could be treated with DDAVP, which is a medicine and has nothing to do with blood. I think researchers discovered by accident that if you were a mild haemophilic or had mild Von Willebrand's, you already had some Factor VIII in you and could use DDAVP to increase your stores. DDAVP did have some side effects and the patient's blood pressure had to be monitored. However, it was a drug as opposed to a blood product so was inherently safer in terms of the risks of infection.

54. The exception to this policy would be surgery, where it was necessary to use blood products on mild haemophiliacs in order to build up their stores. DDAVP couldn't be used for more than one or two treatments at a time.

55. In regard to the information provided to patients about home treatment, as I've mentioned, part of my remit as a Haemophilia Nurse was to visit patients at their homes and teach them how to use home treatment. I would make sure they had everything set up properly, for example having the syringes

locked away and setting up a big tray that was clean and used only for treatment. Patients could also get funding to buy little fridges to keep their treatment separate from their food.

56. In addition to the advice given at home visits, my colleague and I created guidelines for patients on how to treat themselves at home. This was something we prepared ourselves, there was nothing official, as it made sense to do so. The treatment was expensive, so it was important that they knew how to use it properly, exercised care and didn't waste it.

57. I don't remember what the Centre's approach was to obtaining patient consent, but I think it would have been the same as in all other departments at the Heath. When I was working on the Haematology Ward we didn't get patients to sign anything to receive treatment. I don't think there were any guidelines about consent in the 1980's either, and I was never provided with any training or advice later by the Centre in relation to obtaining patient consent.

58. I recall there was a form that patients on home treatment signed to confirm that they would look after their treatment at home. There was an existing form when I started but I think we updated it and turned it into a proper consent form. Patients were also given a form on which to document their use of the treatment. I remember having issues with half the patients never bringing the form back. In terms of how to administer the home treatment, my colleague and I created the guidelines ourselves precisely because there was nothing provided by anyone else. I then visited patients at home and went through the guidelines with them.

59. When Prof died in 1992 there was a bit of hiatus. I can't remember whether the Centre's approach to patient consent changed over time, but I certainly became more cautious and started writing absolutely everything in the patient's notes. I would write "taking patient's blood with consent." It was the same with writing out protocols for the hospital. The patients were generally relaxed and would tell me to take whatever I wanted, but I would say "no, I want you to know what I am doing it for."

60. In my time at the Centre I was never asked or told to withhold information from a patient about risks, treatment, testing, or diagnosis relating to their condition.
61. The frequency in which blood samples were taken from patients really depended on what they came in for and how often they came in. We would probably try and do routine bloods every six months, but if a patient hadn't come into the Centre for a while we might do bloods while they were there. Haemophiliac patients weren't always good at turning up for appointments and sometimes you had to grab them while you could!
62. If patients were having treatment we would do factor assays before and after to make sure they responded to the treatment. This was necessary because some patients had inhibitors and wouldn't respond to all treatments. The turnaround on assay results from the Lab was very quick. We would get the results back straight away if a patient was going into an operation. We also had a couple of patients that were anaemic and came in regularly for blood transfusions. The turnaround on those results from the Lab was also very quick.
63. As far as I can recall, when patients came into the Centre and had bloods taken, it would have been explained what their blood would be tested for. Our patients with HIV or Hepatitis C were generally well clued up with what everything was and were accustomed to the bloods that we carried out. They would come in for their reviews when they were getting treatment for their infections.
64. Sometimes a patient would come in that we hadn't seen for a while, and I am sure in these cases we would have explained why we were taking their blood and what it would be tested for. For example, for patients that had received the Hepatitis B vaccination, we would tell them that we were making sure they were still immune. We didn't often have new patients, and a new patient for us would most likely be a child recently diagnosed with

haemophilia. I eventually started writing everything down, which included recording what we had told the patients about the samples we were taking.

65. If it was discovered that a blood donor had vCJD, the patients who had received product from the batch from that donor would be informed, although I can't remember how this was done. This did occur in my time at the Centre, although thankfully I don't think anyone actually went on to develop vCJD.
66. If patients went to ordinary outpatients their blood would have been taken by a phlebotomist and I can't comment on what information would have been communicated by the phlebotomist.
67. Things changed in the Labs as a result of the knowledge of risks of infection from blood. I am not aware of the ins and outs of it, but I think because of possible risks of contamination the processes in the Lab sped up and results could be given more quickly for serious things.
68. As part of the routine blood tests, liver function tests were undertaken for all patients. Initially the idea was that patients would be tested every six months,. Patients with infections would obviously be tested more regularly. In the early days I think we received results back in a week or so, but things got faster and faster as time went on and new ways of doing things developed.
69. Our procedure for communicating results depended on the particular patient and what we were testing for. If test results were negative, I don't think we would necessarily contact the patient to communicate the results. However, if we were unhappy about a result we would certainly contact them. If we were testing something serious we would likely get the results from the Lab straight away and would tell the patients at the time. If it wasn't serious, we may have communicated the results on the patient's next visit to the Centre.
70. Regular patients and those on treatment for Hepatitis or HIV might phone up for their results, as the tests were a routine part of their treatment and

they were often more alert as to potential problems. Other patients weren't as concerned and might be told the next time they came into the Centre. We had a few patients that simply weren't bothered about hearing their results.

71. I didn't have any involvement in the communication of test results in the early days, except for perhaps contacting patients to inform them they needed to be vaccinated. I think with all other results it would have been a doctor that communicated the results. When we first started testing for HIV I think it would have been Prof, and later on when we started testing for Hepatitis C the patients were being seen by Clinicians and so it was likely the Clinicians informed patients. I don't recall making any calls myself, certainly not in the 1980's.

72. If patients were diagnosed with HIV, HBV or HCV, I think advice was given orally. The advice given really depended on the particular patient. Some of our established patients just wanted to get on with their lives, but others were in all the time and would regularly have one-to-one chats. Sometimes the patients might talk to us nurses, but often they wanted to speak to a doctor. By the late 1980's we had a full-time Clinical Assistant who also would have given advice. Social workers were involved quite a lot as well.

73. I can't recall the Centre or Hospital producing any written advice for patients on the management of HIV, HBV or HCV infections. I don't think there were any leaflets or pamphlets produced nationally for us to disseminate. A lot of the literature was geared towards homosexuals and not necessarily suitable for haemophiliac patients.

74. It was standard practice for the Centre to offer testing to partners of patients infected with HIV, HBV and HCV. I can't recall whether this was offered to patients' children, but I think there were one or two families that asked us to test their children although I am not sure about the outcomes.

75. In terms of counselling and psychological support, most of our patients were happy to speak with a social worker or one of the doctors in regards to their

infections. Some of them would also speak to me or one of the other Haemophilia Nurses.

76. There were some patients that required more support and this was offered.

In the difficult times there was a specialised psychologist that patients could see. I can't remember what his name was. I know for certain that at least one patient saw him, but I don't think many others did. I am not sure how long this continued for.

77. In my time at the Centre there were also social workers available to patients and who did some counselling.

78. I think we started out with one Haematology social worker called Mary Dykes, who I believe was interviewed by the Inquiry last year. Roles evolved and when information about HIV infections from blood products came out we increased to two social workers for a period, and then went back to one. One of the other social workers was called Nia Jones.

79. I could refer patients to a social worker if I thought it was needed. We also had a children's social worker called Judith who I would take with me on home visits to see how the families were getting on.

80. Patients diagnosed with infections were put on whatever treatments came in and were suitable at the time. We saw patients regularly to monitor their treatment. I think this might have happened fortnightly when they first started on treatment and then moved to monthly once they were settled. The prescriptions were a maximum period of a month and were signed off by Clinicians. Some patients fared well with the treatment, but others probably came in quite frequently.

81. I was not involved in prescribing treatment for HIV and HCV. Prescriptions were done at Clinician level. However, when Interferon treatment started in the 1990's, I would show patients how to treat themselves subcutaneously and they would then be sent away to treat at home. Many of the patients were using Factor VIII and were accustomed to administering their own treatments.

82. I know that the treatment for Hepatitis C had huge side effects and for those who first started on Interferon there were many problems. Sometimes if there were complications the patients would be put onto steroids. I can't recall if anyone stopped using Interferon because they couldn't stand it. I think that most patients gritted their teeth and persevered despite feeling awful. I can't recall anyone on HIV treatment stopping their course either.
83. I'm not sure how often patients came in to be monitored but I would have thought it was at least monthly. I presume the length of the course of treatment depended on how the patient was responding. The treatments are so different now and so many people are cleared.
84. If patients had problems relating to their HIV and there wasn't room on the Haematology Ward, sometimes they would be sent to Ward A7 which was part of a Ward dedicated to immune compromised patients generally. The Consultants dealing with HIV were based at Ward A7. Aside from this, there was nowhere else to refer patients to, as our Centre was considered the specialist care unit for those problems.
85. The only time I can recall patients being sent to a different hospital was in the early days before the outbreak of HIV and Hepatitis when orthopaedics moved around a bit. There was a time where haemophiliacs would have to go to a different hospital for orthopaedics, but then thankfully it came back to the Heath for a while before moving to Llandough Hospital about 9 miles away.
86. Clinicians were aware of the infected status of patients due to regular contact with the patients, the patient's notes, and also the small size of our unit. Our Centre treated all patients the same regardless of whether they were HIV, HBV, or HCV positive. I had a good awareness of the stigma that could be attached to these infections, but there was no need for it. However, I am sure that some of our patients would have experienced stigma at some time or other.

87. I liaised with a lot of different departments at the Heath and there was certainly fear in other people about the risks of cross-infection. In the early days when everyone was learning about HIV, I would go around and talk to staff in other departments about haemophilia and HIV to try and allay these fears and debunk some of the myths that flourished.
88. When that A&E nurse carried a patient's case wearing gloves, the patient just smiled at me because I'm sure he knew exactly what was going through my mind. I think after this incident I went to find someone in the nurse's department and asked what their policy was around cross infection. I didn't like the fact that the nurse was wearing gloves because it created stigma.
89. There was another occasion when someone from the Lab asked if a patient was HIV-positive in front of another patient. I asked him to wait outside the door when he had finished and explained that he should never ask that in front of another patient. We took confidentiality seriously at the Centre.
90. There had always been policies on cross-infection on Wards for as long as I had been a nurse. As I have said, the Hospital had an Infection Control team that recognised the risks of cross-infection. I think the policies were kept in a folder, but we just knew what to do, it was something that was instilled into you. Washing hands was a big thing besides anything else, just basic hygiene.

Section 5: Research

91. There was always research going on in the Haematology Department. Part of the remit of Registrars was that they had to spend a certain amount of time undertaking research relevant to haematology. This was part and parcel for every hospital department.
92. In the early days when the Centre had only one room, there were quite a few scientists in the room next to us that were involved in research. Then

when we moved to three rooms, there was actually a proper space with Labs for research. They used this space for amongst other things, genetics research to see if someone was a haemophilia carrier. This was before things progressed and there were tests to check whether the daughter of a carrier was going to be a carrier.

93. In terms of research into HIV and HCV, I think one of my colleagues, Dr Moffat, did some work on immunity. She was looking at this before T-cells were recognised. I think she was seen by the Inquiry a couple of years ago and asked about her research.

94. I honestly don't know whether patients were always made aware of their being involved in research. I know that some patients were brought into the Centre to give their blood for the particular purpose of looking at how to do assays, and they were quite happy to do it. This wasn't just for haemophilia but also for other blood clotting disorders.

95. There was also a family that had a very strange platelets disorder and came in to see a scientist called Dr Giddings to have their blood taken. Dr Giddings was looking at different blood clotting mechanisms. The family knew they had a special syndrome and were very happy to come in.

96. Sometimes the nurses would take the patients' blood when they came in for research purposes, but often the Lab or scientists took the blood. Neither I or the other nurses would have known what the patients had been told by the scientists about the use of their blood.

97. I remember the term 'PUPS' being used at the Centre, but I can't remember much more than it being a term. I presume it meant someone that hadn't received a treatment before, which I suppose would be any new child that had been diagnosed with haemophilia.

Section 6: vCJD

98. I became aware of vCJD when it became known by everyone. From memory that was when it hit the headlines, like everything else. I can't recall learning of it through the hospital. I don't remember who was running the Centre at the time, I think it was after Prof had died, but I am sure whoever it was would have discussed vCJD with all the staff.

99. As I have already mentioned, if a donor was found to have vCJD, the people who had received the batches would be informed. I have a vague recollection of a donor with vCJD presenting in my time at the Centre, and I think the patients who had received the batch were contacted. This would have been communicated at Clinician or Consultant level. I'm not sure if Peter Collins had started by then or if it was a locum.

100. I can't recall what tests you could do in those days to test people for vCJD, but as I have said I don't think any of our patients actually went on to develop it. I can't recall anything produced by the Hospital to provide information to patients about the risks of vCJD.

Section 7: Effect on clinical staff

101. I have provided some comment throughout this statement on the Centre's practices and how they changed to reflect the risks posed to clinical staff, however there wasn't much that could really be changed. Staff simply needed to follow good clinical practice.

102. My knowledge of cross-infection goes back to the 1960's. We dealt with blood from injuries in A&E and simply believed in washing our hands. I was always told to wash my hands and to make sure that the patients saw me washing my hands. Then in the 1970's when I was working on the Haematology Ward, washing my hands was even more important because the patients were often immune compromised. I have seen staff using gloves to feed a patient but don't agree with that. You just need to wash your hands before and after.

103. I don't know when Infection Control started up but must have been at some point after the hospital was built in 1971. I didn't know much about them until I had my needlestick injury. As I have mentioned, I think Infection Control made wearing gloves general policy in the hospital, the idea being that gloves will protect you when you take a needle out. However, if you prick yourself, as I did, the needle always goes through the glove anyway. In addition to wearing gloves we always wore plastic aprons, but once again that didn't always help. I recall a patient's blood transfusion once came apart and I got covered in the content. Yes, the apron helped but only partly.
104. As I have mentioned, the Hospital had an Incident Register kept by Infection Control that would be used to report any concerns or complaints about staff and patient safety. The only time I can recall using the Register was when I had my needlestick injury. I may have made other complaints orally at meetings.
105. As far as I know I never had a patient complain about me or my nursing practice. Nursing is quite a difficult job when you are working so closely with people and you can't get on with everybody. It is the same in all walks of life. Nursing is no different. I would sometimes get comments from patients like "I can tell you've been in the Army."
106. In my time as a Haemophilia Nurse I often felt that haemophiliacs were treated as second class citizens. Prof was obviously appreciative of the situation of haemophiliac patients, but there were many other Haematology Consultants that didn't understand. I recall an instance where I was in the elevator holding treatment for haemophiliac patients and a Consultant in the elevator said to me: "How many thousand pounds of treatment do you have there?" There seemed to be a lack of understanding in some quarters about how vital the treatment was.
107. I appreciate that for what was a small cohort of patients, the treatment bill for haemophiliacs was probably more than it would have been for some chemotherapy treatments. The commercial products were expensive.

108. Once you got to know haemophiliacs however, you realised what their condition meant and what they had missed out on, especially being on bedrest for long periods of time when they were younger. Some patients were brilliant and just got on with things, but a lot had missed out on playing sport and enjoying their childhood, even following their desired career path. You had to think of what they had put up with and put yourself in their position.
109. I still keep in contact with some of the patients I treated. Some of them gave me art for my retirement and I have the pictures up on my wall. I went for a walk recently and saw the parents of two of the boys I had looked after. The oldest is now 34 but the Mum remembered me. Some of the patients have set up a campaign group called Tainted Blood. I really don't like the word 'tainted', but I appreciate it is how they felt about the whole thing.
110. Obviously, many of the patients that I treated contracted infections and have now died, which I was devastated about. I recall seeing the parents of the little fellow who died when he was only seven, on the news and in the Sunday Times. That was quite distressing. It has also been quite hard to read the things in the press about Prof, because most of the patients, I'm quite sure would have spoken very highly of Prof.
111. Despite a number of patients dying, I did not give up my career as a nurse. I carried on in my role. It was the same when I worked on the Haematology Ward in the 1970's and cared for a lot of people who subsequently died. I think it is a generational trait, the ability to deal with sadness and death and bounce back, as my colleague was the same.
112. There wasn't any support provided to staff by the Hospital. Haemophilia Nurses came within the auspices of the Medical Unit, but the Nursing Officer never particularly came to see us. I also can't recall any support being provided from the Royal College of Nursing ('RCN') or Union, but then I did not contact the RCN to ask for support.

113. I suppose I derived some support from talking with colleagues. The World Haemophilia Federation ran big conferences every year and I recall at the first conference in Rio in 1984 I got more out of talking with colleagues than some of the lectures. HIV took over a bit and most of the conferences were centred around this. This was a little bit sad because research in other areas, for example orthopaedics, went a bit static.
114. Ever since the Inquiry contacted me I seem to be dreaming about it and am always thinking of patients, their families and colleagues. I haven't really had anyone to talk to about the Inquiry although I do sometimes bump into people who knew me from my time at the Centre.

Section 8: Other Issues

115. I have been asked whether I recall any of the trusts or funds that were set up to provide financial assistance to people who had been infected. In my time at the Centre I was aware of the Macfarlane Trust. This was the main trust for HIV, and I vaguely recall handouts being available at the Centre. I wouldn't personally refer patients to the Macfarlane Trust but I would contact a social worker and they would arrange it. In my experience, usually the trust was already involved.
116. I have also been asked about the Centre's retention policies in regards to medical records. I don't know anything about the Centre's official retention policy for patient notes and am unaware of any policy to get rid of notes for haemophiliac patients. I am also unaware of clinicians at the Centre keeping any separate records for patients treated with factor concentrates or patients infected with HIV, HBV or HCV.
117. The notes for haemophiliac patients were extensive. There used to be a bit of a joke about them. I knew quite a few older haemophiliac patients from my days on the Haematology Ward, and they probably had three or four

files. They were years old and went right back into that patient's history. Then the notes were kept in filing cabinets which could be locked. Often, they were so big that even trying to get them out was a problem at times. I have arthritic problems in my wrists, primarily from the big cryoprecipitate syringes and taking treatment bottle tops off, but also probably from handling the notes.

118. If patients were just being treated at the Centre then their notes would usually be with us. In the early days when we had only one room, the notes would be kept in a filing cabinet that was always locked. We used to keep our purses in there. When we moved to a larger unit, the unit was locked at the end of the day and you would have to go back behind the desk to be able to access the notes.

119. If patients also went to other departments, for example orthopaedics, their notes would be moved. We didn't always send everything. If the patient had many files we would send the most recent file and anything else relevant. I'm sure systems are probably better nowadays, but when I was at the Centre it was a regular occurrence for notes to go missing between one department and another.

120. Lastly, I have been asked whether I can recall any discussions or interactions with senior clinicians at the Centre, including Prof, about the matters addressed in this statement. I can't recall any particular conversations I had with Prof, Peter Collins, or any of the other senior clinicians that are relevant to them.

121. When Peter Collins started at the Centre we would always have a unit meeting where we would go through who had attended and any issues. We would also have multidisciplinary meetings where a dentist might come across and talk to us about a haemophiliac patient. I can't recall when the multidisciplinary meetings started and whether we had them when Prof was around. After so long I can't remember any specific meetings or the topics discussed.

122. I have had the Use of my Statement form explained to me and have signed it on 11 February 2020 on the basis that it will be submitted once my final witness statement is signed and agreed.

Statement of Truth

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

Signed

GRO-C

Dated

29 JUN 20