Witness Name: Patricia Clegg
Statement No.: WITN3203001
Exhibits: None
Dated: 9th February 2022

INFECTED BLOOD INQUIRY

WITNESS STATEMENT OF PATRICIA CLEGG

I, Patricia Clegg, will say as follows:-

1. My name is Patricia Clegg and I live at GRO-C GRO-C North Wales and my date of birth is GRO-C 1956.

2. I am the widow of John David Clegg. John was a 57 year-old haemophiliac who was co-infected with both the HIV and Hepatitis C viruses. He died in February 2004 from primary liver cancer.

3. I am a retired Nurse, trained in Liverpool, and on our marriage I moved to North Wales where I worked in the local general hospital. For several years prior to my retirement I worked on the Inpatient department of the local hospice.

Section 1: Introduction

4. John and I had no children. When John was diagnosed with HIV we were advised against having children due to the virus being borne in blood and body fluids. So having children was out of the question. My family live on GRO-C so they were near enough to visit regularly and watch my brother's children grow. I have never re-married or entered into any other relationship.

5. I live on my own, in the bungalow where John and I spent our married life. There is not a day that goes by that I do not miss my husband. He was my best friend, knew me better than I knew myself. We shared our problems and worries, although I think he kept a lot of his worries regarding his medical condition to himself.

6. During my widowhood I tried to develop interests and hobbies. Sadly, due to Covid restrictions, some of these have been curtailed, but I hope to pick up these interests again when restrictions ease.

Section 2: How Infected

7. John was born on GRO-C 1946. He was diagnosed with haemophilia as a baby. His diagnosis followed a circumcision when medical staff were unable to control his bleeding. According to information John gave me there was no known bleeding disorders in his mother's family, so some spontaneous gene change took place in John.

8. There followed the type of childhood that most young haemophiliac boys of that time would be familiar with:

   - periods of bed rest due to painful bleeds into joints and muscles, sometimes spontaneous bleeds or bleed due to trauma;
   - missed schooling due to bed rest;
   - painful trips to hospital when bleeds occurred.

   Treatment was by blood transfusion which would require a hospital stay.

9. Despite his missed schooling John was, according to his school reports a "*bright boy who tried hard to catch up with this work*". John battled on with his schoolwork and his Haemophilia and eventually in 1962 obtained three GCE O' Levels whilst at Grammar School in Northwich, Cheshire.

10. John had good numeracy skills, which eventually led to a job as an Audit Clerk. In 1964, he completed a Bookkeeping and Typing course at Commercial College in Blackpool. In 1966 he completed a course with the Society of Company and Commercial Accountants, passing the exam despite having a bleed the evening before his exam.

11. He eventually left his parents' home in Blackpool to live with his grandmother in North Wales. This decision was made due to the worsening relationship with his mother, who in John's opinion blamed herself for his condition. GRO-C GRO-C

12. John eventually got a job with a local accountancy firm and in due course held the position of Accountant and Office Manager. So again John had to contend with his Haemophilia and hold down a job.

13. The introduction of home treatment was seen as a great step forward. An improved lifestyle which meant haemophiliacs could treat their bleeds as soon as they felt symptoms occur.

14. Records obtained from the National Haemophilia Database show John attending Manchester Royal Infirmary Haemophilia Centre. Copies of the MRC Cryoprecipitate Working Party dated 21 October 1969 to 6 December 1970 show that John was treated with Cryoprecipitate, Human AHF (Lister) and fresh frozen plasma for joint, muscle bleeds and some dental extractions.

15. The annual returns for 1971, for Manchester Royal Infirmary patients again show John receiving Cryoprecipitate and plasma, with no inhibitors or jaundice noted. The return for 1972 again shows that Cryoprecipitate and plasma was again used.

16. I did note that on the patient arrival treatment record from the Haemophilia Database that there were two entries from 1969 and 1970 that showed John receiving Factor VIII (BPL). The entry for 1969 I find odd as freeze dried powdered concentrates were not available until the 1970's as far as I am aware, and John had not yet started home treatment.

17. There is the possibility that this was given during a hospital stay, but as I do not have access to John's Manchester Royal Infirmary notes I cannot clarify this. John does mention having an injection of Factor VIII in Manchester Royal, but does not state why he had it, only saying that it stung on administration.

18. From what I can see from John's medical notes from Liverpool, John was treated when an inpatient with mainly Cryoprecipitate and intermittent injections of Factor VIII. Some of the Factor VIII batch numbers have been documented by medical staff.

19. Under the care of Dr Boulton, Consultant Haematologist at the Royal Liverpool John commenced home treatment. Dr Boulton undertook John's instruction on the administration of home treatment.

20. John's own treatment diary starts on 14 August 1978. His first injection was one bottle of Armour Factorate, batch nos. R8312. The products given to John over the years were as follows:

Factor VIII (BPL)
Factorate
Cutter Factor VIII (Koate)
Kryobulin
Oxford Factor VIII
Monoclate P
Kogenate

Recombinate
Hemofil M

21. I am not aware if John was informed of any risks or dangers of using blood products. Looking through John's Liverpool case notes I see no documentation of any conversation regarding any potential problems with blood products used. I cannot remember John ever mentioning any information being given to him when starting home treatment.

22. John had a HIV test in May 1986. According to John's own notes it was either 3 May 1986 or 15 May 1986. John asked the Haematology Consultant at GRO-C GRO-C Glan Clwyd Hospital, for the test. Although John was under the care of Liverpool Centre he attended Glan Clwyd clinic appointments in a type of "pastoral care" type of arrangement. The results were given to John by Dr Edwards, the Consultant who took the sample, during a follow-up clinic appointment.

23. What amount of pre and post counselling took place I do not know as I did not attend the appointment.

24. I did notice on information from the National Haemophilia Database that a sample of blood dated 1 January 1986 appears to have been tested and found to be positive. It could have been that the sample was from stored blood and tested when HIV tests became available. So unless I am mistaken a positive result was known about, but John was not informed.

25. On checking through doctors letters in John's medical notes I cannot see any letters pertaining to the results of John's blood test. Advice given was to not stop injections of Factor VIII as this would be detrimental. And he was also informed of the potential of infecting his wife and therefore the need to wear condoms.

26. With regard to finding out about the Hepatitis C diagnosis. I found out during an Orthopaedic clinic appointment in Liverpool and from what I can remember of the expression on John's face that was also the first he had heard of it. I do not know when John was tested for Hepatitis C or if he was aware.

27. I feel that with regard to both infections John and I should have been informed of the results as soon as possible. If it was known John was HIV positive in January then yes we should have been told and precautions taken sooner.

28. John felt that in the early and mid-80's the risks were played down by certain members of the medical profession and certain Government ministers at the time.

Section 3: Other Infections

29. As indicated above, John was also found to be Hepatitis C positive. I am not aware of when John was tested or if he was aware of being tested for it.

30. As stated above, I found out about the infection during an Orthopaedic appointment at the Royal Liverpool Hospital. I think it was during a joint Orthopaedic/Haemophilia review clinic. It is my belief that this was also the first time John had heard about it.

31. In John's Liverpool case notes there was a letter dated 11 April 1994. It was from Dr Hay (now Professor) who was the Director of the Liverpool centre. I think it may have been the clinic appointment following the Orthopaedic appointment.

32. In the letter it states that John's liver function tests were "*persistently mildly abnormal*", but he was showing no signs of chronic liver disease. The letter also talked about the pros and cons of treatment with Interferon.

33. Other than the HIV and Hepatitis C infections John had the occasional cough and cold which eventually resolved without further intervention.

Section 4: Consent

34. It is difficult to say with the passage of time. John would not have taken any medication without a full explanation of why he was being given them.

35. Whether reports of efficacy of medications or blood results following a course of medication were passed to research establishments I cannot comment.

Section 5: Impact

Mental effects on John and family

36. Mentally John's HIV and subsequent Hepatitis C infection caused him some problems. Acute anxiety was one problem John experienced, especially of social occasions and meeting new people. He even worried about staying overnight at family members' homes.

37. Periods of depression and low self-esteem were also problematic. He worried about holding me back as our social life gradually diminished. He also found it depressing that he had potentially lethal viruses in his body and that he could accidentally infect me. This also impacted our sexual relationship as it was difficult to relax during intimacy so it did put some strain on our relationship at times.

38. John was prescribed anti-depressants which seemed to help. We both found it helpful to talk with the Haemophilia Nurse who was very supportive to us both.

39. Obviously, the fact John had HIV meant we were advised against having children. So, as I note above, we both watched my brother's children grow up. Because of the furore about AIDS/HIV we did not tell family members about John's infection.

40. We married in 1983. Just at that time a "new disease" was being spoken about – AIDS. There were television programmes on the subject and also many newspaper articles about it and the groups of people affected by it, homosexuals, drug users and haemophiliacs.

41. My parents were staying with us at the time when one of these programmes was televised. They were aware John had Haemophilia and the condition was spoken about in the programme. Following the programme my mother broached the subject with me, saying "*Haemophilia – is that what John has?*" However, at that time we were not aware of John's status regarding infection. In fact I do not think that there was a test at the time. It was not the ideal start to married life.

42. When we got John's test results we decided not to inform my family due to the continuing stigma around HIV/AIDS. The only family member I did tell was my mother who I swore to secrecy, and in fairness to her she never told anyone else. In fact my brother only found out when the funeral directors came to collect John's body on the night he died.

43. It was a great strain for us both to keep this secret, but we were both scared of the reaction of family members.

Medical complications

44. The only complications that occurred that I can think of following John's HIV and Hepatitis C infections were John's need for a hip replacement. This took place in Manchester Royal Infirmary in 1996 (he also underwent an elbow replacement

some time later). Both procedures were carried out by Mr P Hirst and his Orthopaedic team.

45. John's Haemophilia was monitored by Dr Hay's team, who, as John was on an Orthopaedic ward, visited every day. His treatment was administered by the Haemophilia nurses if he was unable to carry out this procedure himself.

46. There was unfortunately a problem with the Charnley hip procedure, which caused John some great discomfort, and delayed his rehabilitation. He had a detachment of the greater trochanter which was a "recognised complication of the Charnley Hip Arthroplasty".

47. The elbow replacement went relatively smoothly. Ward staff were efficient and John and I were made to feel comfortable and not stigmatised in any way.

48. John also underwent a gastroscopy for abdominal discomfort. I cannot remember the exact details for this investigation as it was carried out at Manchester Royal Infirmary and I have been unable to obtain John's case notes.

Treatments received

49. John's bloods were taken at each clinic appointment. His CD4 count was monitored and the results of this test would determine if John commenced HIV treatment or not. Whilst at Liverpool his CD4 count started to decline gradually, but he was asymptomatic and therefore no treatment was commenced, according to his case notes.

50. John's care eventually transferred to Manchester Royal Infirmary and Dr Hay moved there to take up his post as Director of the Haemophilia Centre.

51. At Manchester Royal Infirmary John did have to commence HIV treatment as his blood results dropped to a level that needed treatment. He was commenced on various treatment combinations. Some drugs were changed at times due to John suffering side effects. Again, this is from memory as I have no access to his Manchester medical notes.

52. From John's own note from May 2000 I can see that his treatment consisted of the following:

- Stavudine – one tablet at midday, one tablet and midnight;
- Lamivodine – one tablet twice a day;
- Efavirenz – three tablets at night.

Obstacles to obtaining treatment

53. I am not aware of any obstacles that were ever put in John's way regarding treatment. There appeared to be no problem arranging John's hip or elbow replacement surgeries and Hydrotherapy sessions were arranged, when needed, at the local hospital without a problem as far as I know.

Treatments that should have been offered but were not

54. I did wonder why John had never been offered treatment with Interferon. According to a letter in Liverpool medical notes, dated April 1994, "*the pros and cons of treatment of Hepatitis C with Interferon*" were discussed with John, but I do not remember the conversation taking place.

55. As far as I can recall no further discussion took place regarding Interferon therapy during clinic appointments that I attended and nothing regarding further conversations is documented.

56. I just feel had John been given the opportunity, and if he had tolerated the treatment, it could have avoided him dying of Hepatoma. He may not have been able to tolerate the Interferon, but at least he would have tried.

57. I must say that clinic appointments centred mainly on John's HIV condition. From memory his hepatitis status was not mentioned despite regular liver function tests being carried out.

58. In fairness, reference to Hepatitis and liver function test results may have been omitted so as not to give him anything further to worry about and add to his depression.

Mental and physical effects

59. Physical effects of John's medications were trying at times. I recall he did suffer from some side effects of the medications, which, I assume, is why the drug regimes were changed when side effects were reported. I remember that John did complain of feeling nauseated from time to time, so an appropriate anti-emetic was prescribed.

60. One of the things John commented on was how his body had changed. John had always been quite a slim person, however, he had noted his arms and legs were thinner than they used to be. One of his HIV drugs, Stavudine, causes Lipodystrophy, which I think may have been the cause of this.

61. John often commented on the amount of tablets he took daily and said "*it was a wonder he did not rattle*". In total John took approximately 19 tablets a day. These were regular prescription drugs plus his HIV medication. The HIV medication had to be taken at regular intervals, this sometimes led to John taking some tablets at midnight.

62. All of this, plus managing his Haemophilia and trying to work was quite exhausting and stressful. It was no wonder John had episodes of depression. As previously stated, John took refuge in his work. He would feel normal and useful to his clients, and a useful person.

63. I only saw John cry once during this whole situation. We were watching a documentary about an AIDS patient in America. The programme showed a gentleman, looking debilitated and obviously near death. John cried and sobbed, "*please don't let me die like that*". What do you say to that, your husband in mental anguish and scared of dying.

64. John kept a lot of his worries and fears to himself in an effort to stop me from worrying. That was the only time I saw the barrier come down.

Impact on other medical or dental treatment

65. John's infected status did not seem to impact on other medical treatment. He rarely went to our GP. They provided his regular prescription medication. HIV medication was obtained from Manchester Royal Infirmary.

66. John did not go to the local dentist. If dental treatment was ever needed an appointment was made at the Manchester Royal Infirmary.

Private/family and social life for John and our family

67. As previously mentioned above, John and I were advised not to have children following his HIV result. We also made the decision not to inform family members of our situation. We told very few people. Only those we could trust.

68. John felt he had to inform his work colleagues. It was a small office, John worked with three other people whom he had known for years. He had to inform them

because, in case of blood spillage they should be aware. They, thankfully, had no problem, they understood and fully supported him.

69. John also informed two boyhood friends, one who lived in Blackpool and one who lived overseas. They, again, were both supportive of their friend.

70. I told my mother, as previously mentioned, she had asked about the situation regarding HIV and Haemophilia. The rest of my family, as far as I am aware did not know until after John's death.

71. Both of John's parents had passed away. He had a stepbrother who, although he got on with him he was not particularly close to, so John would not have told him. Likewise with John's stepmother, he got on with her, but would not have told her.

72. Unlike John's work colleagues it was somewhat different for me. I worked at the local general hospital so I felt I could not impart such information. I did hear some prejudice against the AIDS situation from untrained staff so I had to be careful with what I said.

73. John wrote that he felt that both he and I had missed out on such a lot due to his fear of social occasions and meeting new people, and his increasing introversion. John's interests became more homebased. He used to go swimming once a week, which he greatly enjoyed but eventually stopped going as he felt uncomfortable.

74. He attended a disabled sports club where he enjoyed, and was extremely good at, pistol shooting. He had to force himself to go to the club. So our world became centred on work and home.

Section 6: Treatment/care/support

75. As previously written, I am not aware of any difficulties or obstacles put in the way of John obtaining treatment due to his conditions.

76. With regard to counselling, I think both John and I seemed to be lucky. At the Liverpool Haemophilia Centre they had a very good Nurse Counsellor – Alison. She was lovely and both John and I got on extremely well with her. We used to see Alison following John's consultations with Dr Hay. She was extremely easy to talk to and I think we both got great benefit from our talks.

77. Alison also did home visits, which I think she enjoyed getting out of the hospital environment. Sadly, Alison left for pastures new. However, both John and I felt she was extremely good at her job. She arranged for relaxation tapes for John to listen to, to hopefully help with his anxiety.

78. John moved to Manchester and we met Meg, a very experienced Haemophilia Nurse Counsellor. Again John and I got on with Meg. When John was diagnosed with his Hepatoma and his condition was deteriorating, Meg very kindly contacted various agencies to obtain some pressure relieving equipment to help make John more comfortable. Following John's death Meg made several home visits for counselling sessions.

Section 7: Financial Assistance

79. From memory John applied to the Macfarlane Trust for a grant to install a central heating system. I cannot remember the exact sum granted, but I do not remember complaining of any great difficulties in obtaining the grant.

80. I think John also asked for help with deposits for his Motability cars which again, from memory was granted. I had little to do with the applications for the grants and so I cannot comment on how difficult the application procedure was.

81. Since the English Infected Blood Support Scheme has been implemented I have had little contact, until recently, with them.

82. I was awarded a winter heating allowance without application. I was also contacted in connection with the Government announcement of March 25 2001, following which I was granted a monthly payment.

Other issues

83. At this present time I can think of no other issues I wish to mention.

84. I feel I could not give evidence in person at the Inquiry, I do not feel brave enough having watched no witnesses give evidence about themselves or their loved ones.

85. I have no qualms about mine or John's name being used if needed.

86. I would like to thank Sir Brian Langstaff and the legal teams at the Inquiry for their patience and understanding. Also the solicitors and their colleagues for their many hours of hard work.

Statement of Truth

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

Signed .....GRO-C..............................

Patricia Clegg

Dated.....9th February 2022.......