SMALLER HAEMOPHILIA CENTRE PRESENTATION

PLYMOUTH

The Centre

1. There was no '*physical or functional centre as such*' at Plymouth.[1] Haemophilia care was provided at the Haematology Department of the District General Hospital.[2] In the 1980s haemophilia care moved to the Derriford Hospital.

2. Despite the absence of a physical centre, this Note will refer to haemophilia care provided at Plymouth as occurring at "the Centre". Haemophilia care was split into adult and paediatric care.[3]

3. Minutes of a Haemophilia Society meeting in 1972 refer to the origins of haemophilia treatment in Plymouth. Professor J. L. Stafford was noted to be leaving St George's Hospital to become the Director of the Blood Transfusion "sub-centre" in Plymouth from 1 October 1972.[4] The notes record that fact that there was '*no organised treatment for haemophilia between [the] Exeter Centre and Truro'* and there was a request for Professor Stafford to *'start something'* in Plymouth. Professor Stafford's recorded response was that he would *'study the situation on arrival and will "help as best I can*". In a meeting of Blood Transfusion Centre Directors, Regional Scientific Advisors and Haemophilia Centre Directors, the creation of associate haemophilia centres in Plymouth, Taunton, Truro, Torbay and Barnstable was raised. It was noted that these areas had '*many summer visitors*' and that the '*roads in the South West are congested and [patients were] travelling long distances to the Haemophilia Centre at Exeter'* which *'could be very time consuming.*'[5]

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[1] §4 of WITN5422001
[2] The hospital was based at Freedom Fields and Greenbank.
[3] S7 of WITN5422001 and WITN7161001
[4] HSOC0029671_003
[5] CBLA0000391

The Directors

4. Dr H Greenburgh and Dr J. L. Stafford are listed as the Centre's directors in January 1977.[6] Dr Greenburgh retired in 1981[7]. The two are described as '*Co-Director[s]*' in UKHCDO minutes.[8]

5. Dr Archibald Grant Prentice then became the Co-Director with Dr Stafford in 1982.[9] He has provided a statement to the Inquiry.[10] Dr Prentice has described the title of Director as an informal title.[11] His role was as a Consultant Haematologist at the District General Hospital. He moved to the Royal Free Hospital, London in 2006 and retired in 2013.

Other staff members

6. In 1975 Dr John Dawson cared for paediatric patients at the Centre.[12]

7. Dr Adrian Copplestone joined the Centre in 1987 when Dr Stafford retired.[13]

8. Dr Tim Noakes then joined the service; Dr Prentice has described Dr Noakes' arrival as '*a big boost to our service.*'[14]

9. In 1993 Dr Michael Hamon joined the Centre.

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[6] HCDO0000085_003
[7] CBLA0001464
[8] CBLA0001619
[9] CBLA0001619
[10] WITN5422001
[11] §5 of WITN5422001
[12] For example, see this letter from Dr Kirk at Treloar's.
[13] §9 of WITN5422001
[14] §10 of WITN5422001

Facilities and staffing at the Centre in 1970s and 1980s

10. Dr Prentice has told the Inquiry that there were no haemophilia clinics run and '*very few patients*' in Plymouth. He describes the facilities in the 1980s in the following terms:

> '*Patients came up initially to the portacabin outside the laboratory (an old, converted, Police Station) and the laboratory would call me to see the patients when they had arrived with bleeds. Sometimes they would call my secretary and the calls to me would come through her. A clinical unit within the hospital was established in 1986 in which patients were subsequently seen.*'[15]

The Blood Transfusion Service

11. The South Western Regional Transfusion Service was the local blood transfusion service to Plymouth. It had headquarters at Bristol but there was also a 'sub-centre' and blood bank based at Plymouth General Hospital, Freedom Fields.[16] There were two donor collection teams working from Plymouth '*but their work is controlled and scheduled from the Bristol Regional Transfusion Centre.*'[17] The testing of the blood donations for hepatitis, AIDS and CMV was carried out at Bristol.[18]

12. In the mid- to late 1980s, Dr Prentice is listed as a staff member for the Plymouth sub-centre.[19]

Treatment policies and blood product usage

13. In addition to the annual returns (which are set out below), the Inquiry has received evidence of the Centre's use of blood products in the mid to late 1970s.

14. In 1976 there is correspondence between the Centre and Treloar's about arranging blood products for children. For example, in May 1976 Dr Kirk wrote to enquire whether it would be feasible for the Centre to supply factor VIII: '*I do not know if*

[15] §13 of WITN5422001
[16] NHBT0006268_002
[17] NHBT0006268_002
[18] NHBT0006268_002
[19] NHBT0006268_002 is undated but likely produced between 1986 and 1987.

other Centres less fortunate than ourselves have been experiencing difficulty in obtaining supplies.'[20] In response, Dr Stafford requested stocks of Hemofil from Treloar's.[21]

15. In 1977 Dr Stafford wrote to Dr Kirk updating him about a patient and stated: '*I feel we really must exert some control over the quantity of Hemofil that he is consuming*.'[22]

16. A March 1978 letter from Dr Stafford sets out the difference in funding available at Treloar's in contrast to the Centre and highlighted the difficulties this caused for treating patients who had come from Treloar's.[23]

17. In a July 1978 letter to Dr Tovey, at the South West Regional Transfusion Centre, Dr Stafford explained the difficulty in expenditure for blood products: '*I am unhappy to have to relate that we are now using the Lister freeze-dried material in excess of income for these two patients'*.[24] He described not wanting to alter one patient's product back to Hemofil '*for psychological reasons*'. He concludes the letter stating: '*I am most apologetic but we are nearly 100% out in our estimated requirement. Can you advise*?' It appears Dr Mayock was able to provide Dr Tovey with some additional supply for these two named patients but not the full amount requested.[25]

18. The Inquiry has also seen a letter from Dr Maycock in March 1978 responding to a letter from one of these two patients. Dr Maycock states he was '*very interested and pleased to receive your letter of the 14th March telling us that you are now using NHS factor VIII concentrate for home treatment having previously been on Hemofil'*. It appears the patient had requested an information leaflet about the product as Dr Maycock wrote:

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[20] TREL0000142_032. See also: TREL0000142_027
[21] TREL0000142_025
[22] TREL0000142_019
[23] CBLA0003023. The Treloar's perspective is here: CBLA0000745
[24] CBLA0000822
[25] CBLA0000828

'*the only literature I could send you is the leaflet which is distributed with the concentrate from her and I imagine that you have already seen this. In the unlikely event that you have not I am sure Dr Stafford, whom you know, will be able to provide one and also be glad to discuss with you all aspects of this concentrate, the use of which he has had much experience.*'

19. There is evidence in June 1984 of Dr Aronstam making arrangements for the potential treatment of a young child visiting Devon on holiday.[26] The blood product being provided is described as from '*an accredited pool of donors*' and is said to be '*low risk material*'. Similar arrangements were made again in 1986.[27]

20. Dr Prentice's recollection of the blood product usage at the Centre is as follows:

'*In terms of the selection, purchasing and use of blood products we went for what was available. We used commercial product as it was often all we could get. I remember constantly trying to find a source of Factor VIII and having difficulty with the availability of the supply. I looked for what was the safest product, but I cannot recall any other criteria. Thus generally decisions were based on what products we could source.*

I do remember discussing the supply of blood and blood products with the South West Centre of the National Blood Service. I cannot remember whether there were discussions with the Regional Health Authority. The Regional Health Authority was a very difficult body to deal with.

The decisions to choose one product over another were not decisions as such. It was as a result of availability of product. Commercial and/or financial considerations played no part whatsoever in any sourcing of blood supply.

I do not remember giving patients a choice as to which product they would be provided with. I may have asked but I do not remember. I do not remember if I could even give a choice. As I have already set out, we had to use what we had.'[28]

21. Dr Prentice has also stated that it may have been the case that the selection and purchase of blood products was '*occasionally carried out by the National blood Service in Bristol. We would certainly get advice from them from time to time. We may also have got it from the Blood Products Laboratory in Borehamwood.*'[29]

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[26] TREL0000126_075
[27] TREL0000126_056
[28] §16-19 of WITN5422001
[29] §24 of WITN5422001

22. Dr Prentice further states:

> '*I always preferred not to give blood or blood product if it could be avoided. I was taught that a pint of blood is a potential biological time bomb. One can never be sure of all consequences however safe a blood product is made.'*[30]

23. He states that he was '*keen to reduce the use of blood wherever possible.*'[31] He describes a rather unusual anecdote: he gave blood as a paid donor in America in 1968 while travelling:

> '*From the other donors around me at that time it was clear to me even then that the supply chain could have been contaminated. I often thought about that when people were talking about commercial blood supplies.*'[32]

24. On 13 June 1985 Dr Prentice wrote to BPL setting out the HTLVIII antibody negative tests of two children and one child who had tested positive. [33]He wrote: '*I presume that you would not be willing to supply him with heat-treated factor VIII concentrate on the grounds that his HTLV III result may be a false positive.*'[34] Dr Prentice stated that there was one child with severe Christmas disease who was HTLV III negative and '*so far untreated.*' The request was made for heat-treated factor IX '*as and when it becomes available.*'[35]

25. In May 1994 Dr Copplestone described his difficulties obtaining 8SM.[36] In a letter to Miss Spooner he wrote:

> '*I am sure the reasons for this are well known to the Reference Centre Directors' (loss of a large amount of Factor VIII) but at a time when BPL is competing with other commercial companies, it makes it very difficult for us to continue to" Buy British". The Reference Centre Directors' Committee needs to bring pressure to BPL to ensure that there was a continuous and adequate supply of High Purity Factor VIII.*'[37]

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[30] §25 of WITN5422001
[31] §26 of WITN5422001
[32] §42 of WITN5422001
[33] See further paragraph 50
[34] BPLL0010533
[35] BPLL0010533
[36] HCDO0000123_069
[37] HCDO0000123_069

Numbers of patients registered and numbers of patients treated

26. The annual return from 1976 states that there were 11 haemophilia A patients and two patients with haemophilia B treated that year.[38] The treatment provided was cryoprecipitate, NHS factor VIII and IX, Hyland's Hemofil and a small amount of Immuno's Kryobulin. No patients were noted to have died that year.

27. The annual return from 1977 states that there were 18 haemophilia A patients and one patient with haemophilia B treated that year.[39] The treatment provided was cryoprecipitate, NHS factor VIII and IX, and Hyland's Hemofil. No patients were noted to have died that year.

28. The annual return from 1978 states that there were nine haemophilia A patients and one patient with haemophilia B treated that year.[40] The treatment provided was cryoprecipitate, NHS factor VIII and IX, and Hyland's Hemofil. No patients were noted to have died that year.

29. The annual return from 1979 states that there were eight haemophilia A patients and one patient with haemophilia B treated that year.[41] The treatment provided was cryoprecipitate, NHS factor VIII and IX, and Hyland's Hemofil. No patients were noted to have died that year.

30. The annual return from 1980 states that there were eight haemophilia A patients and one patient with haemophilia B treated that year.[42] The treatment provided was cryoprecipitate, NHS factor VIII and IX, and Hyland's Hemofil.

31. The annual return from 1981 states that there were 12 haemophilia A patients and three patients with von Willebrand's disease treated that year.[43] The treatment provided was cryoprecipitate, NHS factor VIII and IX, and Hyland's Hemofil.

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[38] HCDO0001109
[39] HCDO0001195
[40] HCDO0001292
[41] HCDO0001362
[42] HCDO0001460
[43] HCDO0001560

32. The annual return from 1982 states that there were nine haemophilia A patients and one patient with von Willebrand's disease treated that year.[44] The treatment provided was cryoprecipitate, NHS factor VIII and IX, and Hyland's Hemofil.

33. The annual return from 1983 states that there were around nine[45] haemophilia A patients, two patients with haemophilia B.[46] Dr Prentice is marked as the sole Director on the return. There was a change in treatment with no cryoprecipitate used. The treatment used was NHS factor VIII and IX, Armour's Factorate and Hyland's Hemofil.

34. The annual return from 1984 states that there were 11 haemophilia A patients and three patients with haemophilia B.[47] The treatment used was cryoprecipitate, NHS factor VIII and IX, and Armour's Factorate.

35. The annual return from 1985 states that there were nine haemophilia A patients, five patients with haemophilia B and three patients with von Willebrand's disease.[48] The treatment used was cryoprecipitate, NHS factor VIII and IX, and Armour's Factorate.

36. The annual return from 1986 states that there were nine haemophilia A patients, two patients with haemophilia B and two patients with von Willebrand's disease.[49] The treatment used was cryoprecipitate, NHS factor VIII and IX, Armour's Factorate, Cutter's Koate, Immuno's Kryobulin.

37. The annual return from 1987 states that there were five haemophilia A patients, four patients with haemophilia B and two patients with von Willebrand's disease.[50] The treatment used was cryoprecipitate, NHS factor VIII and IX, Alpha's Profilate, Cutter's Koate, Immuno's Kryobulin.

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[44] HCDO0001659
[45] The number on the front of the return is not completed.
[46] HCDO0001755
[47] HCDO0001849
[48] HCDO0001944
[49] HCDO0000337_004
[50] HCDO0002128

Knowledge of risk of hepatitis and response to risk

38. Correspondence with Miss Spooner at Oxford refers to the use of hepatitis surveys at the Centre in 1975.[51] In November 1975 Dr Kirk from Treloar's wrote to Dr Dawson about a hepatitis study being carried out by Dr Kirk:

'*if he could be restricted to Cryoprecipitate for his replacement therapy I would be most grateful. Furthermore, it would be helpful if a blood sample (10 ml. clotted blood x 2) could be taken once during the Christmas and Easter vacations and once a month during the summer holiday*.'[52]

39. In relation to HBV, correspondence between the Centre and Dr Kirk at Treloar's in 1975 reveals knowledge of HBV: '*we have not checked for Australia antigen*'.[53] Dr Prentice's evidence is that he was aware of HBV because he was exposed to it as a senior registrar when working in Glasgow.[54] The Inquiry has seen drug incident report forms for a patient testing positive for HBV in late 1987 after treatment with Koate HT.[55] A different patient also tested positive for HBV in 1988. At the bottom of the reporting form the following is written:

'*HBsAg associated with Cutter product as 2 others who had the same batch have also developed hepatitis B*.'[56]

40. This led Dr Copplestone to notify both Cutter and Miss Spooner about the HBV infection in three patients.[57] Cutter responded that all plasma used had been screened and found to be negative, additional test results were negative and they had no other reports of HBV from these batches.[58] It appears that the batches were withdrawn.[59]

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[51] HCDO0000038_002
[52] TREL0000142_033
[53] TREL0000244_041
[54] §44 of WITN5422001
[55] BAYP0000011_096
[56] HCDO0000256_147
[57] HCDO0000256_002
[58] BAYP0000011_027
[59] BAYP0000005_056

41. In relation to non-A non-B hepatitis / HCV, Dr Prentice is unsure when he first became aware of non-A non-B hepatitis / HCV.[60]

Numbers of HCV infections

42. In 1996 Dr Copplestone described there being '*a little uncertainty about the original number of patients who have received concentrate factor and it may be more than 16…It is possible that more will come to light in due course.*'[61]

Testing for HCV and communication of diagnosis

43. One witness describes that in 1992 when he requested an HIV test, as he and his wife wanted to start a family, he was also tested for HCV unbeknownst to him.[62] He states he was first informed of his HCV infection in 1994.[63] This was despite the fact that contemporaneous medical records state his first positive test was in 1992.[64]

Treatment for HCV

44. In 1996 Dr Copplestone, in a letter from Dr Davies at Taunton, described HCV care in the following terms:

'*Our basic policy is to manage these patients in collaboration with Dr. Steven Wilkinson, our Hepatologist His policy so far has been to monitor the liver function tests and asked me to arrange PCR tests which have been performed at Edinburgh. Many of the patients are currently being reviewed by him in… light of the results to make a decision about alpha interferon treatment.*

He is currently discussing this with the purchasers to obtain funding but I do not think this is a major problem as we are able to treat them as part of the general haematology pool of patients.

I have also been sent an Alpha Interferon and Ribavirin trial to consider. There are only a few patients that would be eligible here because of the age criteria and

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[60] §44 of WITN5422001
[61] TSFT0000002_025
[62] §14 of WITN1721001
[63] §17 of WITN1721001
[64] §18 of WITN1721001

I enclose a copy - perhaps it might be better to treat the patients regionally in this trial. I would be interested to know what you think.'[65]

45. Dr Prentice's evidence is that haemophiliacs with HCV were treated by a gastroenterologist.[66]

46. The Inquiry has received statements from infected individuals and their families describing the physical challenges of HCV treatment.[67]

Knowledge of risk of AIDS and response to risk

47. Dr Prentice states that his knowledge of HTLVIII / AIDS developed over time by reading about it and discussing it with colleagues. He states: '*I have no specific detail of when I first became that there might be an association between Aids and the use of blood products.*'[68]

48. In relation to the risk of transmission of AIDS he states:

'*I cannot recall any specific enquiries carried out by me or within the Plymouth Haematology Department in relation to the risks of transmission of HIV or Aids. Patients were seen frequently to discuss all aspects of their care and it is likely that these discussions would have included the risks of viral transmission through the use of blood products but I cannot recall any such specific discussions.*'[69]

HIV

49. Provisional UKHCDO data available to the Inquiry suggests that there were six patients with HIV at the Centre by 1988.[70]

50. Whilst Dr Prentice's recollection, as set out in his statement,[71] was that there were no children infected with HIV at the Centre, other evidence available to the Inquiry indicates that this is not correct:

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[65] TSFT0000002_025
[66] §90 of WITN5422001
[67] For example, WITN1580001
[68] §47 of WITN5422001
[69] §48 of WITN5422001
[70] INQY0000250
[71] §69 of WITN5422001

a. A letter dated 13 June 1985 from Dr Prentice to Mr Pettett at BPL identified one young boy who was HIV positive. [72]

b. Whilst Dr Prentice's letter referred to the possibility that the result could be a false positive, sadly the Inquiry knows that it was not. The young boy in question – only three years old at that time – was infected with HIV through factor concentrates, developed AIDS Related Complex, and died in 1992, aged just 10 years old: see the statement of Sarah-Jane Ward, his sister, and Troy Price, his brother, which describes the appalling treatment he, and the family, suffered.[73]

Arrangements for testing patients for HTLV III and informing them of their diagnosis

51. Dr Prentice's evidence is that he told people of their diagnosis with HIV face to face.[74]

52. One patient who was transferred from Cardiff under the care of Professor Bloom was found to be HTLV III positive in January 1987.[75] The patient's family disputes any suggestion that he was '*extensively counselled*' either at Cardiff or Plymouth about his HIV.[76]

53. In September 1988 Dr Copplestone wrote to Dr Rizza at the Oxford Centre about the test results for two haemophiliacs who had tested positive for HIV.[77]

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[72] BPLL0010533
[73] WITN7159001
[74] §61 of WITN5422001
[75] WITN2406016
[76] WITN2406015 and WITN256001.
[77] CBLA0002420

UKHCDO / South West Haemophilia Treaters Group

54. Dr Copplestone was invited, along with the other consultant haematologists in the area, to attend the South West Haemophilia Treaters Group organised by Dr Helena Daly.[78] He attended a meeting on 10 May 1991.[79]

55. Dr Prentice states that he was not a member of UKHCDO but attended UKHCDO meetings on an occasional basis.[80]

Pharmaceutical companies

56. Dr Prentice's evidence is:

> '*I do not recall any relationships between the Plymouth Haematology Department and the pharmaceutical companies. We bought products on a commercial basis if we required to do so. I do not recall visits from sales reps and if I was asked to see sales reps, I would generally say no.*'[81]

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SEPTEMBER 2021, AMENDED NOVEMBER 2023

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[78] TSFT0000001_001
[79] TSFT0000001_026
[80] §30 of WITN5422001
[81] §22 of WITN5422001