SMALLER HAEMOPHILIA CENTRE PRESENTATION

BATH

The Centre

1. The Bath Haemophilia Centre was based at the Area Central Laboratory, Royal United Hospital, Combe Park, Bath ("the Centre").

2. The Centre was not a UKHCDO reference centre but had a relationship with Bristol, Cardiff and Oxford reference centres.[1]

The Directors

3. Dr Ray L. Holman was the director of the Centre from around 1977 to 1986.[2]

4. According to the annual return in 1986, Dr Janet Thomas and Dr John Graham Smith became co-directors at the Centre that year.[3] However, by 1987 Dr John Graham Smith is the only director listed on the annual return[4] and Dr Smith was the sole director of the Centre from 1987 onwards. He remained a Consultant Haematologist of the Royal United Hospital ("RUH") until 2003.[5]

Other staff members

5. From early 1970s Dr Sam D. V. Weller was a paediatrician treating child haemophiliacs at the Centre.[6]

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[1] See HSOC0017872
[2] One patient states that Dr Holman left the Centre in 1984. The witness describes that at that time there was 'a lack of a full-time Haematology Consultant' which he believes had a detrimental impact on his overall medical care: §96 of WITN1013001. He states there was then an improvement in care from 1987 onwards.
[3] HCDO0001974
[4] See also HCDO0000357_013 where Dr Smith stated he was without another consultant.
[5] §2 of WITN4491001
[6] OXUH0003779_002. Dr Weller was still in post in 1978: WITN1013011

6. A J. M. Cusworth[7] signed a Hepatitis Survey Form in 1980.[8]

7. Before becoming Centre director in 1986, Dr Janet Thomas was working as a locum consultant haematologist in March 1984.[9] She is listed as an Associate Specialist in September 1991.[10]

8. Dr E. L. Blundell worked as a Senior Registrar in 1986.[11]

9. A Dr Jones is listed as the Centre's contact for a Koate HT recall in 1988.[12]

10. In or around May 1991 Dr Charles Singer was a Consultant Haematologist at the Centre.[13]

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

11. The Inquiry does not have a complete picture about the facilities and staffing at the Centre in the 1970s and 1980s.

12. From the early 1970s patients with haemophilia received orthopaedic treatment at the RUH. In March 1972 Dr Weller, Consultant Paediatrician, wrote to Dr Biggs at the Oxford Infirmary asking for advice about treatment of haemarthrosis in patients with haemophilia.[14] Dr Weller described '*one or two new orthopaedic surgeons who are very keen that they should aspirate these joints at the earliest possible moment and we have some more traditional ones who regard this procedure with horror.*'[15] He requested advice on whether children should be

[7] The handwriting is fairly hard to read so it is difficult to be certain about this spelling.
[8] HCDO0000257_001
[9] HCDO0000229_011
[10] WITN1013011. It therefore seems unlikely that she was in fact Director of the Centre in 1986 as suggested by the annual return of that year.
[11] WITN1013009; WITN1013010
[12] BAYP0000005_057
[13] HSOC0017872
[14] The Inquiry has received a written statement from one such patient who in 1970 spent 16 weeks as in inpatient at the Centre due to a knee bleed and now has haemarthropathy in his knees: WITN1013001
[15] OXUH0003779_004

given cryoprecipitate before or after such a procedure. In another letter in April 1972 to Dr Biggs, Dr Weller stated:

'*For purposes of treating haemophilia this Hospital is regarded as a 'Centre'. Our problem is that we have Orthopaedic Surgeons with differing views on this particular problem and the management of patients is therefore not very easy to have [a] uniform [view].*'[16]

13. It appears that care for haemophiliacs in the 1970s was divided into care under the haematology department and the paediatric department.[17] However, Dr Holman continued to have an input into paediatric care.[18]

14. In 1987 Dr Smith expressed his dissatisfaction with staffing levels at the Centre. In a letter to Dr Rizza dated 30 November 1987, he wrote:

'*I apologise for the delay in getting [the annual return] to you but as I am single handed and 19.1 consultant sessions down on the average for England and Wales then I believe I have an excuse not helped by the fact that JPAC is trying to take away my 1 and only Senior Registrar.*'[19]

15. By 1991 Dr Singer was working as an additional consultant at the Centre.[20]

The Blood Transfusion Service

16. As with other centres in this region, the Bath Centre was served by the South West Regional Transfusion Centre.

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[16] OXUH0003779_002
[17] OXUH0003779_002: '*he had already had some doses of Cryoprecipitate at the instigation of the haematology Department, though quite possible not on the instructions of the Consultant Haematologist.*'
[18] See, for example, WITN1013005. In 1979 this patient transferred from paediatric care to care under the haematology department.
[19] HCDO0000357_013
[20] HSOC0017872

Treatment policies and blood product usage

17. The Centre's annual returns are set out in the section below.

18. In line with other centres, it appears that the standard treatment for children in the early 1970s was cryoprecipitate administered as part of inpatient care. In an April 1972 letter, Dr Weller describes one child as being '*in the Ward almost once a week and is no stranger to repeated doses of cryoprecipitate.*'[21]

19. The Inquiry has received a statement from an individual who first received factor VIII, as well as cryoprecipitate, in 1977 whilst an inpatient and aged around 11 years old. The treatment received was a mix of NHS factor VIII and commercial products.[22] There is some evidence that he was allergic to cryoprecipitate. He began home treatment in April 1979[23] after being given information and training at the Centre by Dr Holman.[24]

20. The Inquiry has received witness evidence about haemophiliacs being on home treatment in the mid 1980s.[25]

21. On 1 February 1985, Dr Janet Thomas, the locum Consultant Haematologist, wrote to Dr Terry Snape at BPL to request heat-treated Factor VIII for nine named patients with haemophilia A. This appears to be all of the patients who were regularly treated at the Centre. Three were listed as being HTLV-III negative, whilst the remaining six patients' HTLV-III results had not yet been received.[26]

22. The Inquiry has received evidence from a patient who began to receive heat treated products in March 1985.[27] The same patient received a letter in October

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[21] OXUH0003779_002
[22] §9 of WITN1013001
[23] §11 of WITN1013001
[24] WITN1013005
[25] For example, see §9 of WITN1037001
[26] BPLL0010661
[27] §96 of WITN1013001

1986[28] regarding the recall of Armour heat treated product. The witness discusses the letter in his statement to the Inquiry:

'*Armour, the manufacturers of the Factor VIII blood products widely used, had recalled certain batches of their heat treated product. No explanation or timeframe was given for this; I was simply asked to return any unused product to the laboratory at my own convenience. On checking my personal treatment records I identified that I had finished using one of these batches a few weeks before.*

I spoke to the Doctor at the RUH who issued the letter and was informed about the HIV implication. She referred to two "previously untreated patients (PUPs)" in Birmingham becoming HIV positive following the use of one of these Armour products. A HIV test was offered again, which I took and was also negative. I remember the night of the phone call, locking myself away in my bedroom in the dark and not wanting to speak to anyone and being very quiet for at least the following week. I kept on working and coaching swimming as usual and never discussed the situation with anyone and just "buried it" deep within.'[29]

23. He describes that up to the 1990s '*protocols were rather informal if not "homely" with my RUH haemophilia centre.*'[30] He describes being able to:

'*walk directly into the blood bank to collect my Factor VIII home treatment supplies and speak to the doctor's secretary to get my regular blood test results. In stark contrast to today's infection control protocols during various hospital admissions in 1975, 1976 and 1977, I was allowed to keep the syringes that had been used for my injections. Once they had been cleaned under running tap water in the treatment room I would distribute them to other children on the ward -*

[28] WITN1013010
[29] §31-32 of WITN1013001
[30] §15 of WITN1013001

being normally 30mls in size they made excellent water pistols and plasticine pellet guns!'[31]

Numbers of patients registered and numbers of patients treated

24. The annual return from 1977 states that the Centre treated six patients with haemophilia in that year.[32] There was one patient with von Willebrand's disease. The blood products used were cryoprecipitate, NHS factor VIII and Cutter's Koate. There were no deaths recorded that year. Two patients were noted to be jaundiced in 1977-1978. No patients were on regular home therapy.

25. The annual return from 1978 states that the Centre treated six patients with haemophilia A and one with haemophilia B in that year.[33] One patient with von Willebrand's disease was treated and they received cryoprecipitate. The blood products used were NHS factor VIII and IX, Armour's Factorate and Hyland's Hemofil, as well as a very small amount of NHS factor IX. No deaths were recorded during the year. Two patients were noted to be on regular home treatment.

26. The annual return from 1979 states that the Centre treated 10 patients with haemophilia A and one with haemophilia B in that year.[34] One patient with von Willebrand's disease was treated and they received cryoprecipitate. The blood products used were NHS factor VIII, Armour's Factorate and Hyland's Hemofil as well as a very small amount of NHS factor IX. No deaths were recorded during the year. Five patients were on regular home therapy.

27. The annual return from 1980 states that the Centre treated 12 patients with haemophilia, two patients with haemophilia B and two with von Willebrand's

[31] §15 of WITN1013001
[32] HCDO0001135
[33] HCDO0001229
[34] HCDO0001298

disease in that year.[35] The blood products used were NHS factor VIII and IX, Armour's Factorate and Hyland's Hemofil.

28. The annual return from 1981 states that the Centre treated seven patients with haemophilia, one patient with haemophilia B and three with von Willebrand's disease in that year.[36] The blood products used were NHS factor VIII and IX, Armour's Factorate and Immuno's Kyrobulin.

29. The annual return from 1982 states that the Centre treated eight patients with haemophilia and one patient with haemophilia B.[37] The blood products used were NHS factor VIII and IX, Armour's Factorate and Immuno's Kyrobulin. There were three patients with von Willebrand's disease who were treated with cryoprecipitate.

30. The annual return from 1983 states that the Centre treated seven patients with haemophilia A, one patient with haemophilia B and two with von Willebrand's disease in that year.[38] The blood products used were cryoprecipitate, NHS factor VIII and Immuno's Kryobulin. The haemophilia B patient received NHS factor IX. Three patients were noted to be on regular home treatment.

31. The annual return from 1984 states that the Centre treated ten patients with haemophilia A and one patient with haemophilia B that year. No patients with von Willebrand's disease received treatment.[39] The blood products used were cryoprecipitate, NHS factor VIII, Immuno's Kryobulin and one patient received DDAVP. The haemophilia B patient received NHS factor IX. Six patients were noted to have received home treatment.

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[35] HCDO0001392
[36] HCDO0001491
[37] HCDO0001594
[38] HCDO0001690
[39] HCDO0001787

32. The annual return from 1985 states that the Centre treated nine patients with haemophilia A exclusively in hospital. One patient with factor XI deficiency was also treated. No patients with haemophilia B or von Willebrand's disease were seen at the Centre.[40] The blood products used were cryoprecipitate, NHS factor VIII, Armour's Factorate, Immuno's Kryobulin, DDAVP, Tranexamic acid and 12 bags of plasma.

33. The annual return from 1986 was co-signed by Drs Janet Thomas and John G Smith. It states that the Centre treated nine patients with haemophilia A. No patients with haemophilia B or von Willebrand's were seen at the Centre.[41] The blood products used were NHS factor VIII, Armour's Factorate and a small amount of Immuno's Kryobulin. In addition to those already listed, Cutter's Koate was also used for home treatment, which seven patients regularly received. No patients were noted to have died that year.

34. The annual return from 1987 states that the Centre treated 11 patients with haemophilia A and one patient with haemophilia B. No registered patients with von Willebrand's disease received treatment from the Centre.[42] The blood products used were cryoprecipitate, NHS factor VIII and Cutter's Koate. The patient with haemophilia B was treated with NHS factor IX in hospital. Six patients are noted as receiving regular home treatment.

35. On 23 March 1988, the Centre was notified by Cutter that it was recalling Koate HT Batch No. 50S021.[43] This was due to a possible hepatitis B transmission at Plymouth Haemophilia Centre. Bath Haemophilia Centre returned six vials of the implicated batch, which were replaced by Cutter.[44] The Inquiry has not been able to locate the annual returns for 1988, so it has not been possible to ascertain whether this batch was prescribed to any patients registered at the Centre.

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[40] HCDO0001878
[41] HCDO0001974
[42] HCDO0002067
[43] BAYP0000005_057
[44] BAYP0000011_058

36. The annual return from 1989 states that the Centre treated nine patients with haemophilia A and one patient with haemophilia B. No patients with von Willebrand's were treated by the Centre that year.[45] The blood products used were NHS factor VIII, Armour's Monoclate and Cutter's Koate. The haemophilia B patient received NHS factor IX for home treatment. Seven of the nine haemophilia A patients were noted as receiving home treatment.

Knowledge of risk of hepatitis and response to risk

37. It is not clear from the available material the extent of Dr Holman's knowledge about the relationship between blood products and hepatitis.

38. The Inquiry has received written evidence from one patient who developed HBV over the New Year period in 1977 to 1978 after being treated with a mix of NHS and commercial factor VIII concentrates.[46] He states:

'At the time it was believed that I did not get it from the blood products I had received during Autumn 1977 ... as my surface antigen was negative. In 1984 it was identified that I was Hepatitis B core antigen positive but surface antigen negative'.[47]

39. In April 1980, J. M. Cusworth[48] notified Rosemary Spooner at Oxford Haemophilia Centre of a suspected case of hepatitis in a patient who had received 974 units of Immuno's Kryobulin in March that year. He was reported as being *'unwell but ambulant',* with symptoms beginning in April 1980, and including jaundice, anorexia, nausea and raised LFTs, amongst others. He was also reported as having received treatment with large pool freeze-dried concentrate in 1977.[49]

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[45] HCDO0002250
[46] §9 of WITN1013001
[47] See §34 of WITN1013001, WITN1013011 and WITN1013012
[48] The handwriting is fairly hard to read so it is difficult to be certain about this spelling.
[49] HCDO0000257_001

Numbers infected with HCV

40. It is not clear from the available evidence the numbers of patients that were infected with HCV.

Testing for HCV and communication of diagnosis

41. One patient with haemophilia describes his HCV testing and diagnosis in the following terms:

'*During the Christmas period in 1990 I felt quite unwell and a general malaise for about three weeks. I mentioned this at my next review in June 1991. It was also early in 1991 that the RUH had the ability to do Alanine Aminotransferase (ALT) liver enzyme testing. My May and June 1991 results were "above normal" and higher than my first ALT result in March 1991. As a result, investigations began in earnest for possibility of Hepatitis* C.'[50]

42. A sample of his blood from 1985 which had been kept in storage, alongside samples from 1988 and 1990, was tested and demonstrated that he had HCV.[51] He was aware in 1985 that such samples were being stored.[52] He was told he had HCV on 15 August 1991 by his Consultant Haematologist. He was told that '*since 1988 they had suspected I had it due to my liver function test results, however, I was not told of their suspicion at the time.*'[53] He was then referred to a Consultant Gastroenterologist at the RUH. He states that he does not think he could have been diagnosed more quickly '*albeit ignoring the previous 3-year suspicion.*' He states that the diagnosis was discussed with him on at least 4 face-to-face consultations.[54]

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[50] §38 of WITN1013001
[51] §39 of WITN1013001, WITN1013013 and WITN1013014
[52] §7 of WITN1013001
[53] §40 of WITN1013001
[54] §42 of WITN1013001

Treatment for hepatitis

43. On 15 August 1991 Dr Smith wrote in response to a letter from Dr Ian Fraser at the Regional Transfusion Centre. He suggested that Bath's Consultant Physician and Gastroenterologist, Dr Michael Davis, would be able to assist in the clinical care of hepatitis C antibody-positive individuals.[55]

44. On 29 October 1991, Dr Michael Davis wrote to Dr Nicola Anderson, Consultant Haematologist at the South Western RTC, confirming his willingness to assist in the care of anti-HCV positive patients.[56]

45. The Inquiry has received evidence from a witness about treatment for HCV, including Interferon.[57] Counselling was offered in 1998 and in the early 2000s to one patient with HCV.[58] However, he was unable to access sufficient counselling on the NHS and had to pay privately.[59]

Knowledge of risk of HIV and response to risk

46. It is not clear from the available material the extent of Dr Holman's knowledge of the risk of HIV and his response to risk. He attended the UKHCDO meeting on 17 October 1983 where AIDS was discussed.[60]

47. One haemophiliac recalls *'being told by the RUH that they tried to source factor VIII products from Europe rather than American if they were unable to get NHS supplies.'*[61] He further recalls that his parents and other patients attended a Haemophilia Society Bristol and South West local group AIDS Seminar held in

[55] NHBT0075690
[56] NHBT0075688
[57] §45 of WITN1013001
[58] §66 of WITN1013001
[59] §107 of WITN1013001
[60] PRSE0004440
[61] §27 of WITN1013001

Cardiff by Professor Bloom. He is unable to recall the date of the meeting or what was discussed at the meeting.[62]

Testing and communication of diagnosis of HIV/AIDS

48. The Inquiry has received a statement from a haemophiliac who had a physical examination of his lymph nodes on 15 November 1984.[63] On 11 December 1985 he had his first blood test for HIV. He states that these became quarterly tests for a period of around three years. The frequency of testing was then reduced to six-monthly tests from 1989 to 1996 and then annual tests up to 2004 when he left the Centre.

49. This witness further states that the result of a May 1986 blood test was set out in a '*simply worded letter*'.[64] He recalls a conversation with one of the Centre secretaries who told him that any reference to HID/AIDS was omitted from the letter '*to reduce the risk of discrimination/harassment following an incident at Portsmouth hospital where the results of a haemophiliac boy was disclosed by a member of staff resulting in dog faeces being posted through the family's home letterbox.*'[65] He further states that '*I was also told at the same time that the "carbon copy" of a result letter was not placed on patients file[s] to reduce the risk of inappropriate disclosure.*'[66]

Numbers infected with HIV

50. Provisional UKHCDO data available to the Inquiry suggests that a total of three patients were infected with HIV in the years up to and including 1988. One patient seroconverted (or first tested positive) in 1983. Two patients seroconverted (or first tested positive) in 1985.[67]

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[62] §28 of WITN1013001
[63] §29 of WITN1013001
[64] WITN1013009
[65] §30 of WITN1013001
[66] §30 of WITN1013001
[67] INQY0000250

Treatment for HIV

51. The Inquiry has received evidence about the use of AZT,[68] inpatient treatment with transfusions and monthly check ups at the Centre.[69] The surviving partner of an infected haemophiliac states that he had '*a good relationship with the doctors at the RUH.*'[70] The surviving partner was provided counselling by the Centre, including bereavement counselling.[71]

UKHCDO

52. Dr Holman attended a number of UKHCDO meetings including the 10th meeting of the UK Haemophilia Centre Directors on 10 November 1979,[72] the 12th meeting of the UK Haemophilia Centre Directors on 9 October 1981[73] and the 13th meeting of the UK Haemophilia Centre Directors on 13 September 1982.[74] However, no recorded contributions from Dr Holman are minuted.

JENNI RICHARDS QC

TAMAR BURTON

INQUIRY COUNSEL TEAM

3 October 2021

[68] For example see §12; §22 of WITN1037001
[69] §22 of WITN1037001
[70] §34 of WITN1037001
[71] §55 of WITN1037001
[72] BPLL0007384
[73] CBLA0001464
[74] CBLA0001619