SMALLER HAEMOPHILIA CENTRES PRESENTATION
UNIVERSITY COLLEGE HOSPITAL (UCH), LONDON

Directors, staffing and facilities

1. The Directors of the Haemophilia Centre at UCH during 1970s-80s included Professor T A J Prankerd and Dr J D M Richards. It appears that Professor Prankerd was Director of the Centre from around 1968 to 1977. Dr Richards was Director of the Centre from around 1977 to at least 1989.

2. Other personnel at UCH included Dr Paula Bolton-Maggs and Dr Goldstone, both of whom attended meetings of UKHCDO. The Inquiry has received a witness statement from Dr Bolton-Maggs dated 17 November 2020.[1] Dr Bolton Maggs was a part time registrar at UCH working 3 sessions per week from 1980 to 1983, then working 5 sessions per week with on-call responsibilities until late 1986.[2] In April 1986, she was promoted to Senior Registrar.[3] Dr Bolton-Maggs described her role at UCH as follows:[4]

> *"I concentrated on coagulation, and attended the Regional Haemophilia Directors meetings in London on behalf of UCH. There were several other trainees (senior registrars) in the department who shared in the management of patients with bleeding disorders. Patients would attend outpatient clinics or had drop in visits to the haematology department. My role would have included writing treatment plans for patients with bleeding disorders who were undergoing surgery and the treatment of outpatients presenting with bleeding. Around 1980 I believe that I suggested the introduction of desmopressin for mild haemophilia and von Willebrand disease in preference to plasma products, which was agreed by Dr Goldstone. I was assisted by the Senior MLSP in coagulation, Linda Wilkinson. I do not recall any haemophilia nursing support for outpatients."*

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[1] WITN4160001
[2] WITN4160001 para 5.1
[3] WITN4160001 para 5.1
[4] WITN4160001 para 6.1.3

3. Dr Bolton-Maggs described the facilities at UCH as follows:[5]

> "*The haemophilia patients would usually be seen as outpatients in the haematology department. As far as I recall there was no formal haemophilia centre at UCH.*"

4. Regarding senior colleagues, Dr Bolton-Maggs explained:[6]

> "*As my role was as a part-time Registrar at UCH, I was supervised by the consultants (Drs Goldstone and Richards) and Dr Sam Machin at the Middlesex. My recollection is that overall supervision of haemophilia and bleeding disorders was provided by Dr Machin*."

5. Dr Bernard McVerry has provided a written statement dated 19 November 2020.[7] Dr McVerry undertook a position as a Senior Registrar at University College Hospital in around 1975 and was there for approximately five years.[8] He was not however involved with haemophiliacs.[9]

Status of Haemophilia Centre, Relationship with other Haemophilia Centres and Relationship with Regional Blood Transfusions Centres

6. The Haemophilia Centre at UCH was based at the Department of Haematology, University College Hospital, Gower Street, London, WC1E 6AU.

7. In 1970, UCH was one of 13 designated Haemophilia Centres in the London area.[10] Dr E Huehns attended a meeting of Directors of Haemophilia Centres in London on 15

[5] WITN4160001 para 6.1.1
[6] WITN4160001 para 6.1.2
[7] WITN3502004
[8] WITN3502004 para 2.2
[9] WITN3502004 para 2.2
[10] DHSC0100026_009 and OXUH0003597. The 13 designated Haemophilia Centres in the London area at that time were Guy's Hospital, St Mary's Hospital, King's College Hospital, Royal Free Hospital, Hospital for Sick Children (Great Ormond Street), Lewisham Hospital, University College Hospital, Westminster Hospital, St Thomas' Hospital, The London Hospital, St George's Hospital, The Middlesex Hospital, Hammersmith Hospital.

October 1970 on behalf of UCH at which the organisation of Haemophilia Centres in London was discussed.[11]

8. By letter dated 17 November 1976, Dr W d'A Maycock wrote to Dr Richards at UCH stating that from December onwards, concentrate previously supplied by the Blood Products Laboratory would have to be obtained from the Regional Transfusion Centre.[12] From the end of 1976, NHS factor VIII concentrate was distributed through the Regional Blood Transfusion Centres. With some slight adjustments, it was said that this corresponded to the supply areas of the appropriate Blood Transfusion Centres at Brentwood, Edgware and Cambridge.[13]

9. UCH was part of the North-East Thames Region (Region 06). On 29 November 1976, Dr Dormandy of the Royal Free Hospital wrote to all Haemophilia Centre Directors in Regions 04 (East Anglia), 05 (North-West Thames) and 06 (North-East Thames) including Professor Prankerd.[14] At that time, Professor Ingram of St Thomas' Hospital and Dr Dormandy of the Royal Free Hospital, both Haemophilia Reference Centres, were asked to be jointly responsible for the South-East Haemophilia Supraregion. Dr Dormandy and Professor Ingram decided to split the Supraregion along the Thames. UCH, being in the northern half (comprising East Anglia Region (04), North-West Thames Region (05), and North-East Thames Region (06)), fell under the responsibility of Dr Dormandy.[15]

10. At a meeting of Directors of Haemophilia Centres/Associate Haemophilia Centres (Regions 04, 05 and 06) and Blood Transfusion Centres on 15 December 1976,[16] it was noted that the distribution area of the Regional Blood Transfusion Centre at Edgware did not coincide with Region 05 and that the NHS factor VIII supply had been adjusted

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[11] OXUH0003597
[12] CBLA0000486
[13] CBLA0000506
[14] CBLA0000506
[15] See also: CBLA0000533 minutes of meeting on 15 December 1976 where it is recorded that "*Professor Ingram and Dr Dormandy, who were the reference Centre Directors for regions 04-08, had taken the Thames as a dividing line so that Professor Ingram would be mainly concerned with regions south of the Thames (07/08) and Dr Dormandy with regions north of the Thames (04, 05 and 06).*"
[16] CBLA0000533

to account for this.[17] Specfically, "*the Edgware BTC supplies cryo and blood to the RFH and UCH, both of which are now in the NETHA*".[18] Although UCH was part of the North-East Thames Region, it was noted that it was outside of the "Brentwood Parish" i.e. the distribution area of Brentford RBTC:[19]

> "*RFH and UCH are both in the NETRHA but outside the Brentwood Parish. Adjustments need to be made to the allocation of NHS F.VIII concentrate to Brentwood and Edgware if each Director is to supply only his own 'parish'*."

11. Dr McVerry attended on behalf of Professor Prankerd a further meeting of Directors of Haemophilia Centres/Associate Haemophilia Centres (Regions 04, 05 and 06) and Blood Transfusion Centres on 23 September 1977.[20] Dr McVerry reported that there was a shortfall of NHS concentrate at UCH due to more patients on home treatment (HT) which required them to purchase commercial concentrates:[21]

> "*Dr McVerry: UCH needed 40-45 bottles NHS conc./month as they now had 3 more patients on HT. They were currently purchasing 20-25 bottles (4,400-5,500 u) Hemofil / month to make good this shortfall. They wanted 20-25 extra bottles of NHS conc./month. Dr Dormandy pointed out that the addresses of the patients should be taken into account in deciding whether Brentwood or Edgware should supply the extra needed.*"

12. Dr Richards on behalf of UCH attended a further meeting of Directors of Haemophilia Centres/Associate Haemophilia Centres (Regions 04, 05 and 06) and Blood Transfusion Centres on 1 September 1978.[22] This issue of shortfall of NHS concentrate was raised again:[23]

> "*Dr Richards reported on a patient of his who had severe reactions to cryoprecipitate. They were having to spend about £400 per month on*

[17] CBLA0000533
[18] CBLA0000533 p. 2
[19] CBLA0000533 p. 2-3
[20] BART0000689 / CBLA0000657
[21] BART0000689 / CBLA0000657 p. 3
[22] CBLA0000838
[23] CBLA0000838 p. 4

commercial concentrates for him because they were short of NHS concentrate. The burden was on the Haematology Department which was trying to find the funds."

13. The response from Dr Lane was recorded as follows:[24]

> "*Dr Lane felt he didn't have much to say on this matter except that more was being spent on commercial factor VIII by the DHSS than was spent on the entire budget for the NHS fractionation programme. They were in a position to process more fresh frozen plasma than they were receiving. If they could get more finance from the Department of Health, to double the production of factor VIII in the next few years, it would go a long way towards alleviating the present problems. However, the financial difficulties of the Blood Transfusion Service and the Department of Health could not be discussed at this meeting.*"

14. It was also recorded that "*Dr Richards said deliveries of commercial concentrates were slow and mentioned that he had had to pay an extra £70 for an urgent delivery*".[25]

15. An article published in the British Medical Journal in 1977 provided some information about Haemophilia Centres in the North East Thames Region.[26] Specifically, Table II shows the number of patients cared for at each Centre and treated at home. At UCH, there was 1 patient with haemophilia receiving cryoprecipitate and 1 patient receiving concentrate for home treatment.

16. There appear to have been regular meetings of the Association of Haematologists in the North-East Thames Region. Dr Bolton-Maggs attended one such meeting on 1 October 1983.[27] It was recorded that the number of patients on home treatment resident in North East Thames at UCH on 1 October 1983 was 4.[28] Dr Bolton-Maggs also attended further meetings on 13 December 1984[29] and 25 June 1986.[30] According to her written

[24] CBLA0000838 p. 4
[25] CBLA0000838 p. 5
[26] HSOC0022537
[27] BART0000678
[28] BART0000678 p. 2
[29] BART0000676
[30] BART0000673

statement, Dr Bolton-Maggs could not recall what happened at the meeting on 13 December 1984.[31]

Numbers of Patients treated and/or registered at the Centre

17. In response to a request for information from the Department of Health and Social Security in December 1969,[32] Professor Prankerd indicated in his response dated 20 January 1970 that:[33]

    a. There were 29 cases registered at the Centre;
    b. There were 32 incidents of haemorrhage for which patients attended the Centre for treatment;
    c. There were 3 haemophiliac patients not registered with the Centre who attended for treatment;
    d. There were 4 incidents of severe bleeding in patients attending the Centre;
    e. There were 4 major surgical operations undertaken in patients registered with the Centre during the year;
    f. No patients with incidents of severe bleeding or major surgical operations were transferred to the Special Treatment Centre at Oxford.

18. In late 1972, Professor Prankerd responded to a survey, for the attention of Dr Maycock of the Blood Products Laboratory, in which he indicated that there were 8 patients treated regularly.[34]

19. A list of Haemophilia Centres suggests that there were 11 patients with haemophilia A UCH in around 1975.[35]

20. In the following years, the numbers of patients registered and/or treated at UCH from the available evidence were as follows:

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[31] WITN4160001 para 36
[32] DHSC0100026_016
[33] DHSC0100026_014
[34] BPLL0008111 / CBLA0000092 4
[35] OXUH0000863_002

a. 1976: The Annual Returns for 1976, signed by Prof Prankerd, recorded that the Centre treated 12 patients with haemophilia A including 1 patient with factor VIII antibodies.[36] Of the 12 patients with haemophilia A, the notes suggest that 1 patient was on regular home therapy and 2 other patients were due to commence home therapy shortly.[37]

b. 1977: The Annual Returns for 1977, signed by Prof Prankerd, indicate that the Centre treated 7 patients with haemophilia A, including 1 patient with factor VIII antibodies, 1 patient with Christmas disease and 2 patients with von Willebrand's disease.[38]

c. 1979: The Annual Returns, signed by Dr Richards, report that the Centre treated 3 patients with haemophilia A, and no patients with Christmas disease.[40]

d. 1980: The Annual Returns for 1980, signed by Dr Richards, indicate that the Centre treated 8 patients with haemophilia A, 3 patients with von Willebrand's disease, and 4 patients with haemophilia B.[42] It appears there were 34 registered patients with haemophilia A, 3 registered patients with haemophilia B, and 8 registered patients with von Willebrand's disease.[43]

e. 1981: The Annual Returns for 1981, signed by Dr Richards, report that the Centre treated 7 patients with haemophilia A, 2 patients with von Willebrand's disease, and 4 patients with haemophilia B.[44] There appear to have been around 35 registered patients with haemophilia A, 6 registered patients with haemophilia B, and 19 registered patients with von Willebrand's disease.[45]

f. 1982: The Annual Returns for 1982, signed by Dr Richards, indicate that 7 patients with haemophilia A, 5 patients with von Willebrand's disease, and 3

[36] HCDO0001124
[37] HCDO0001124
[38] HCDO0001214
[40] HCDO0001381
[42] HCDO0001479
[43] HCDO0001479
[44] HCDO0001583
[45] HCDO0001583

patients with haemophilia B were treated at the Centre.[46] There appear to have been 35 registered patients with haemophilia A, 6 registered patients with haemophilia B, 21 registered patients with von Willebrand's disease.

g. 1983: The Annual Returns for 1983, signed by Dr Richards, show that the Centre treated 5 patients with haemophilia A, 1 carrier of haemophilia A, 8 patients with von Willebrand's disease, and 3 patients with haemophilia B.[47] There appear to have been around 37 registered patients with haemophilia A, 1 registered carrier of haemophilia A, 6 registered patients with haemophilia B, 39 registered patients with von Willebrand's disease.[48] The Centre did not treat any haemophilia A patients with factor VIII antibodies,[49] or haemophilia B patients with factor IX antibodies.[50]

h. 1984: The Annual Returns for 1984, signed by Dr Richards, show that the Centre treated 7 patients with haemophilia A, 1 carrier of haemophilia A, 6 patients with von Willebrand's disease, 1 patient with haemophilia B and 1 carrier of haemophilia B.[51] It appears there were around 37 registered patients with haemophilia A, 7 registered patients with haemophilia B, 1 registered carrier of haemophilia A, and 41 registered patients with von Willebrand's disease.[52]

i. 1985: The Annual Returns for 1985, signed by Dr Richards, indicate that the Centre treated 6 patients with haemophilia A, 2 carriers of haemophilia A, 7 patients with von Willebrand's disease, 1 patient with haemophilia B, 1 carrier of haemophilia B and 1 patient with factor XI deficiency.[53] It appears there were around 39 registered patients with haemophilia A, 6 registered patients with haemophilia B, 3 registered carriers of haemophilia A, 1 registered carrier of haemophilia B, 51 registered patients with von Willebrand's disease, and 10

[46] HCDO0001678
[47] HCDO0001775
[48] HCDO0001775
[49] HCDO0000227_006
[50] HCDO0000227_004
[51] HCDO0001869
[52] HCDO0001869
[53] HCDO0001964

registered patients with factor XI deficiency.[54] A list of haemophiliacs treated within NWT RHA with NHS heat-treated factor concentrate in April 1985 shows 2 patients under the care of Dr P Bolton-Maggs at University College Hospital.[55]

j. 1986: The Annual Returns for 1986, signed by Dr Richards, show that 3 patients with haemophilia A, no carriers of haemophilia A, 3 patients with von Willebrand's disease, and 1 haemophilia B patient were treated at the Centre.[56] There appear to have been 41 registered patients with haemophilia A, 7 registered patients with haemophilia B, 3 registered carriers of haemophilia A, 1 registered carrier of haemophilia B, and 54 registered patients with von Willebrand's disease.[57]

21. Data from UCH was contributed by Professor Prankerd, Dr Richards and Dr Goldstone to published studies including: Jaundice and Antibodies Directed Against Factors VIII and IX in Patients Treated for Haemophilia or Christmas Disease in the United Kingdom by Rosemary Biggs,[58] Haemophilia Treatment in the United Kingdom from 1969 to 1974 by Rosemary Biggs,[59] and Treatment of haemophilia and related disorders in Britain and Northern Ireland during 1976-80 by C R Rizza and Rosemary J D Spooner.[60]

Treatment policies and blood product usage

22. In response to a questionnaire for Dr Maycock, BPL, in November 1972, Professor Prankerd indicated the preferred treatment for patients with haemophilia was not cryoprecipitate but freeze-dried concentrate. [61] He estimated that he required 1,500 bottles of freeze-dried concentrate annually for the present treatment policy. It was noted in manuscript that "*one patient at present on weekly prophylactic cryo – 20*

[54] HCDO0001964
[55] BPLL0010517_002
[56] HCDO0000372_004
[57] HCDO0002058
[58] HCDO0000581
[59] PRSE0004645
[60] HCDO0000586
[61] BPLL0008111 p. 30

bags".[62] If the supply of cryoprecipitate and/or concentrate were not restricted by shortage, Professor Prankerd estimated that he would require 1,500-2,000 bottles of freeze-dried concentrate annually.

23. In 1974, Professor Prankerd signed a statement saying "I agree that a British Standard for Factor VIII should be made available for use at Haemophilia Centres after supplies of the current 4th Standard are exhausted".[63] The statement appears to have been signed in response to a letter from Rosemary Biggs.[64]

24. Dr Bolton-Maggs did not recall exactly what products were available at UCH. She stated:[65]

> "*In the early years I remember treating haemophilia and von Willebrand disease patients with cryoprecipitate. Some patients were on home treatment with cryoprecipitate. Concentrate was becoming available both from the NHS and commercial companies. I did not have any authority to decide which concentrates were to be used, but the focus was to use NHS-derived concentrates if possible. At this time the concentrates were not heat-treated. The data about what was used will be available in the UKHCDO Annual Returns submitted to UKHCDO.*"

25. The available information from UKHCDO suggests that the following blood products were used in the following years:

    a. 1976: The Centre used 1,373 bottles / 274,600 units of cryoprecipitate, 45 bottles / 13,300 units of NHS factor VIII concentrate, 10 bottles / 3,100 units of Hyland Factor VIII (Hemofil), 2 bottles / 400 units of Immuno Factor VIII (Kryobulin), and 94 bottles / 25,620 units of Lister factor VIII.[66]

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[62] BPLL0008111 p. 30
[63] OXUH0003865_051
[64] OXUH0003865_053
[65] WITN4160001 para 8.1
[66] HCDO0001124

b. 1977: In total, the Centre used 104,790 units of cryoprecipitate and 67,800 units of NHS factor VIII.[67] For von Willebrand's disease patients, the Centre used 234 bottles / 16,380 units of cryoprecipitate. For treatment of haemophilia A patients (excluding home therapy), the Centre used 180 bottles / 13,500 units of cryoprecipitate, and 6 bottles / 1,440 units of NHS factor VIII.[68] For home treatment of haemophilia A patients, the Centre used 1,000 bags / 75,000 units of cryoprecipitate and 300 bottles of NHS factor VIII.[69] It was noted in manuscript in the comments section that:

> "*We run very close to stock with factor VIII from the Lister – We requested a raising of our quota as our main supply of home therapy is to a patient who has just become married and is not responding too well to his usual dose of 25 bags cryo/week & 10 bottles of conc once month*"

c. 1979: In total, the Centre used 60 bottles / 4,200 units of cryoprecipitate, 20 bottles / 60,000 units of NHS factor VIII, and 1,235 bottles / 126,000 units of Hyland Factor VIII (Hemofil).[70] It appears that 2 patients on home therapy were treated with a combination of NHS factor VIII (Elstree) and Hyland Factor VIII (Hemofil). The 1 patient who was treated in hospital received cryoprecipitate.[71]

d. 1980: For treatment of haemophilia A patients in hospital, the Centre used 300 packs of cryoprecipitate, 200 bottles of NHS factor VIII, 560 bottles of Hyland Factor VIII (Hemofil), and 4 bottles of Immuno Factor VIII (Kryobulin).[72] For home treatment of haemophilia A patients, the Centre used 200 bottles of NHS factor VIII, 500 bottles of Hyland Factor VIII (Hemofil), and 4 bottles of Immuno Factor VIII (Kryobulin).[73] To treat 3 patients with von Willebrand's disease, the Centre used 180 packs of cryoprecipitate in hospital and 30 packs

[67] HCDO0001214
[68] HCDO0001214
[69] HCDO0001214
[70] HCDO0001381
[71] HCDO0001381
[72] HCDO0001479
[73] HCDO0001479

of cryoprecipitate for home treatment.[74] To treat 4 patients with Christmas disease in hospital, the Centre used 50 bottles of NHS factor IX.[75]

e. 1981: Although the figures are not easy to read, it appears that, to treat haemophilia A patients in hospital, the Centre used 67,130 units of cryoprecipitate, 46,750 units of NHS factor VIII, and 21,500 units of Immuno Factor VIII (Kryobulin). For home treatment of haemophilia A patients, the Centre used 65,500 units of NHS factor VIII, 10,400 units of Hyland Factor VIII (Hemofil) and 63,000 units of Immuno Factor VIII (Kryobulin).[76] To treat 2 patients with von Willebrand's disease in hospital, the Centre used 6,300 units of cryoprecipitate.[77] To treat 1 haemophilia A patient with factor VIII antibodies, the Centre used 13 bottles / 3,320 units of NHS factor VIII. To treat 4 patients with haemophilia B, the Centre used 74,400 units of NHS factor IX concentrate in hospital.[78]

f. 1982: For hospital treatment of haemophilia A patients, the Centre used 2,170 units of cryoprecipitate, 84,594 units of NHS factor VIII, and 18,750 units of Immuno Factor VIII (Kryobulin).[79] For home treatment of haemophilia A patients, the Centre used 42,500 units of NHS factor VIII, and 1,439,780 units of Immuno Factor VIII (Kryobulin). To treat 1 haemophilia A patient with factor VIII antibodies, the Centre used 9,530 units of NHS factor VIII. To treat patients with von Willebrand's disease, the Centre used 6,300 units of cryoprecipitate, and 1 patient was treated with DDAVP.[80] To treat 3 patients with haemophilia B in hospital, the Centre used 13,970 units of NHS factor IX.[81]

g. 1983: To treat haemophilia A patients in hospital, the Centre used 145,455 units of NHS factor VIII, 2,000 units of Armour Factor VIII (Factorate), and 74,517 units of Immuno Factor VIII (Kryobulin). For home treatment of haemophilia

[74] HCDO0001479
[75] HCDO0001479
[76] HCDO0001583
[77] HCDO0001583
[78] HCDO0001583
[79] HCDO0001678
[80] HCDO0001678
[81] HCDO0001678

A patients, the Centre used 125,143 units of NHS factor VIII, and 14,000 units of Immuno Factor VIII (Kryobulin). To treat 1 carrier of haemophilia A, the Centre used 2,000 units of Armour Factor VIII (Factorate), and 2,000 units of Immuno Factor VIII (Kryobulin).[82] To treat 8 patients with von Willebrand's disease in hospital, the Centre used 80 bags of cryoprecipitate and DDAVP.[83] For treatment of haemophilia B patients, the Centre used 14,840 units of NHS factor IX in hospital and 4,980 units of NHS factor IX for home treatment.[84]

h. 1984: To treat haemophilia A patients in hospital, the Centre used 2 bags of plasma, 745 bags of cryoprecipitate, and 1,500 units of NHS factor VIII. For home treatment, the Centre used 135,650 units of NHS factor VIII, and 14,980 units of Kryobulin (HT).[85] To treat 1 carrier of haemophilia A, the Centre used DDAVP, and to treat 6 von Willebrand's disease patients in hospital, the Centre used 11 bags of plasma and 170 bags of cryoprecipitate.[86] For home treatment of 1 haemophilia B patient, the Centre used 6,000 units of NHS factor IX. To treat 1 carrier of haemophilia B in hospital, the Centre used 1,800 units of NHS factor IX.[87]

i. 1985: To treat haemophilia A patients in hospital, the Centre used 40,430 units of NHS factor VIII, and 3,200 units of Alpha Factor VIII (Profilate).[88] For home treatment of haemophilia A patients, the Centre used 98,415 units of NHS factor VIII, 8,640 units of Alpha Factor VIII (Profilate), and 63,627 units of Immuno Factor VIII (Kryobulin).[89] to treat 1 carrier of haemophilia A, the Centre used DDAVP. For treatment of 7 patients with Christmas disease in hospital, the Centre used 12 units of plasma, and 481 bags of cryoprecipitate.[90] For home treatment of 1 patient with haemophilia B, the Centre used 6,350 units of NHS factor IX, and to treat 1 carrier of haemophilia B at home, the Centre used

[82] HCDO0001775
[83] HCDO0001775
[84] HCDO0001775
[85] HCDO0001869
[86] HCDO0001869
[87] HCDO0001869
[88] HCDO0001964
[89] HCDO0001964
[90] HCDO0001964

tranexamic acid.[91] 1 patient with factor XI deficiency was treated with tranexamic acid.[92]

j. 1986: To treat haemophilia A patients in hospital, the Centre used 17,550 units of Alpha Factor VIII (Profilate).[93] For home treatment of haemophilia A patients, the Centre used 203,130 units of NHS factor VIII, and 27,960 units of Alpha Factor VIII (Profilate). To treat 3 patients with von Willebrand's disease in hospital, the Centre used 6 units of plasma and 44 units of cryoprecipitate.[94] For 1 patient with haemophilia B, the Centre used 5,000 units of NHS factor IX in hospital.[95]

26. Regarding the use of alternative treatments to factor VIII concentrates during the 1970-1980s, Dr Bolton-Maggs stated:[96]

> "*12.1 In the 1970s I believe that concentrates gradually became available. Otherwise Haemophilia A was treated with cryoprecipitate and haemophilia B with plasma.*
>
> *12.2 Factor concentrates became available in the 1980s for both haemophilia A and B so the use of cryoprecipitate gradually diminished. Some FVIII concentrates were also effective for more severe forms of von Willebrand disease. Desmopressin was used for mild haemophilia A and mild von Willebrand disease (vWd) in the early 1980s.*
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> *12.3 In both decades antifibrinolytics were available and used for example for dental extractions as additional treatment, or as sole treatment for nose bleeds and heavy menstruation (oral contraceptive pills were also useful for menorrhagia).*"

[91] HCDO0001964
[92] HCDO0001964
[93] HCDO0000372_004
[94] HCDO0000372_004
[95] HCDO0000372_004
[96] WITN4160001 para 12

27. Dr Bolton-Maggs explained that "*Desmopressin is a non-blood product*".[97] She stated that she "*introduced this in preference to concentrate for mild haemophilia and mild von Willebrand disease (vWd)*".[98]

28. Regarding the treatment policy at UCH, Dr Bolton-Maggs stated:[99]

> "*Cryo was used for patients with von Willebrand disease and for some patients with haemophilia A but I do not recall the policy. Concentrates were introduced once they were available and this policy weas not decided by me.*"

29. For treatment of people with mild or moderate bleeding disorders, Dr Bolton-Maggs stated:[100]

> "*UCH – factor concentrates were used for mild haemophilia until the introduction of desmopressin in the early 1980s. This was not suitable for factor IX deficiency nor patients with moderate haemophilia A. Factor IX concentrate was preferable to fresh frozen plasma for haemophilia B at all levels of severity where replacement therapy was required.*"

30. Regarding heat-treated products, Dr Bolton-Maggs stated that:[101]

> "*The aim was to use these as soon as they were available. I do not recall how these were obtained for patients at UCH, nor can I recall how non-heat-treated products were used at this time. The only information I have is that provided in the minutes of the association of haematologists of NE Thames haemophilia working party (BART0000676). By the time I was at Alder Hey all patients were receiving heat treated products.*"

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[97] WITN4160001 para 13.1
[98] WITN4160001 para 13.2
[99] WITN4160001 para 14.1
[100] WITN4160001 para 18.1
[101] WITN4160001 para 38.1

31. Specifically, Dr Bolton-Maggs did not remember the process for obtaining heat-treated product or the correspondence with Dr Snape at BPL dated 1 February 1985 regarding heat-treated Factor VIII for two patients.[102]

32. Dr Bolton-Maggs could not comment on the reliability of studies referred to in a letter from a Cutter representative dated 9 July 1986,[103] which were said to show that Koate HT carried no risk of LAV/HTLV III transmission and a low risk of transmitting NANB hepatitis, and could not remember what products were used at UCH.[104]

33. Dr Bolton-Maggs stated that she did not know what the policy was for home treatment or when it was introduced.[105] She later stated in her written statement that:[106]

> "*Home treatment was encouraged for children with severe haemophilia A as it resulted in a much better life-style and quicker treatment. The risks as well as benefits would have been explained. To the best of my knowledge heat treated factor VIII products were available for children which were considered low risk. The risk of inhibitor development would have been explained and the need to screen regularly for that. Parents and children would have had a programme of education for home treatment mainly provided by the haemophilia sisters. They could have contact by telephone for any queries. Prophylaxis was easier with home treatment. Parents varied in their abilities but with encouragement and training they were able to achieve it. At appropriate ages (variable) the child would learn to administer their own treatment.*"

34. Dr Bolton-Maggs recalled treating one child at UCH but not many as they would normally have been managed from Great Ormond Street Hospital.[107] A list of centres with patients under the age of 19 suggests there were some such patients at UCH.[108]

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[102] CBLA0011265. WITN4160001 para 39.1. Further correspondence with Dr Snape is at BPLL0010626, BPLL0010516 and BPLL0010515
[103] BAYP0000008_276
[104] WITN4160001 para 43
[105] WITN4160001 para 15.1
[106] WITN4160001 para 53.1
[107] WITN4160001 para 17.1
[108] HCDO0000013_269

Knowledge of risk of hepatitis/HIV and response to risk

35. Professor Prankerd was often represented by a colleague at UKHCDO meetings during his time as Director. On 1 October 1968, Professor Prankerd sent his apologies and was represented by Dr E Huehns on behalf of UCH.[109] On 5 April 1971, Dr E Bennett represented UCH.[110] On 27 October 1972, Professor Prankerd sent his apologies and was again represented by Dr Enid Bennett.[111]

36. Professor Prankerd was also represented on several occasions by Dr J D M Richards, including on 31 January 1974,[112] 1 November 1974,[113] 24 October 1977,[114] and 13 November 1978.[115] Dr B A McVerry was also in attendance on 13 November 1978 in addition to Dr Richards.[116] At the meeting on 13 January 1977, Professor Prankerd sent his apologies and was represented by Dr A H Goldstone on behalf of UCH.[117]

37. In response to a letter from Dr Rizza dated 17 February 1977,[118] Dr Richards suggested in a letter dated 25 February 1977, [119] that the order of priority of topics for UKHCDO working parties should be:

> "*1. Home treatment of Haemophilia.*
> *2.Prophylaxis in Haemophilia.*
> *3. Management of Haemophilia with factor VIII anti-bodies.*"

38. In addition to those meetings he attended on behalf of Professor Prankerd, Dr Richards attended several UKHCDO meetings during his time as director of the Centre at UCH,

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[109] HCDO0001013
[110] HCDO0001014
[111] HCDO0001015
[112] CBLA0000187
[113] HCDO0001017
[114] PRSE0001002
[115] HSOC0010549
[116] HSOC0010549
[117] PRSE0002268
[118] Although this letter is addressed to Dr Maycock, a letter to Professor Prankerd was likely to have been in materially the same terms as CBLA0000575
[119] OXUH0000490_002

including on 9 October 1981,[120] 27 September 1984,[121] and 25 September 1987.[122] On 9 October 1981, Dr A H Goldstone was also in attendance together with Dr Richards on behalf of UCH.[123] Dr Richards sent his apologies for several UKHCDO meetings, including on 20-21 November 1979,[124] 13 September 1982,[125] 17 October 1983,[126] 21 October 1985,[127] 17 March 1986,[128] 9 October 1986,[129] 29 September 1988, [130] and 9 October 1989,[131] although it is assumed that he would have been sent the minutes of the meeting and therefore would have been aware of what had been discussed. On at least three of those occasions, UCH was represented by Dr Bolton-Maggs in attendance at the meetings on 21 October 1985,[132] 17 March 1986,[133] and 9 October 1986.[134]

39. It does not appear that Professor Prankerd, Dr Richards or Dr Goldstone contributed to the Glasgow Symposium on Unresolved problems in Haemophilia in 1980,[135] or the Manchester Symposium on Current Topics in Haemophilia in 1982.[136] An annual meeting of the British Society for Haematology took place on 27-29 March 1985 where it appears that Dr Richards and Dr Goldstone contributed to presentations.[137]

40. Dr Bolton-Maggs stated:[138]

> "*When I worked at UCH, I became aware that there could be infections associated with blood products. The sources of information would have been medical meetings, medical literature, UKHCDO and colleagues.*"

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[120] DHSC0002339_048 and CBLA0001464
[121] PRSE0003659
[122] HCDO0000485
[123] DHSC0002339_048 and CBLA0001464
[124] CBLA0001028
[125] CBLA0001619
[126] PRSE0004440
[127] PRSE0001638
[128] PRSE0001688
[129] PRSE0004317
[130] BART0002329
[131] HCDO0000015_035
[132] PRSE0001638
[133] PRSE0001688
[134] PRSE0004317
[135] RLIT0001242
[136] DHSC0002221_003
[137] BSHA0000120
[138] WITN4160001 para 20.1

41. She further stated:[139]

> "*There was some evidence that the risk of infection with hepatitis viruses and HIV was increased with commercial concentrates sourced from the USA compared with NHS, but infections were also transmitted by UK products, both concentrates and cryoprecipitate*."

42. Dr Bolton-Maggs described her understanding of the nature and severity of the different forms of blood borne viral hepatitis as follows:[140]

> "*27.1 HAV would usually be a mild infection with full recovery and subsequent immunity. It had rarely been transmitted by blood products.*
>
> *27.2 Evidence of past HBV infection was not uncommon in adults and children treated with blood products prior to heat treatment but was mostly asymptomatic and with evidence of immunity.*
>
> *27.3 The impact of NANB hepatitis was not fully appreciated for some time. It became apparent that a number of patients with NANB developed evidence of chronic liver damage.*"

43. In relation to HIV, Dr Bolton-Maggs stated:[141]

> "*It was known before the virus was identified, that the condition could be transmitted by blood transfusion, so it was not surprising to find evidence of immune dysfunction and illness in haemophilia patients in the early 1980s (before the virus was identified in 1983-4 and a test developed in 1984-6). Understanding and knowledge of HIV and AIDS evolved as further research was published and information shared at the UKHCDO and other meetings*."

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[139] WITN4160001 para 22.1
[140] WITN4160001 para 27
[141] WITN4160001 para 28

44. In response to when she first became aware that there may be an association between AIDS and the use of blood products, Dr Bolton-Maggs stated:[142]

> "*I cannot now be certain but I would say the early 1980s. Bruce Evatt from the Center for Disease Control in Atlanta USA had cases reported to him in 1982, e.g. haemophilia patients diagnosed with pneumocystis pneumonia. There were also papers in Lancet 1984 and NEJM 1984.*"

45. Regarding precautions taken, Dr Bolton-Maggs stated:[143]

> "*My recollections now are that there would have been caution in the management of venepuncture and IV treatment, adopting the same procedures as for HBV, i.e. gloves for venepuncture and treatment, double bagging of samples and labelling them as high risk with yellow hazard stickers*."

46. In relation to investigations taken in response to knowledge of risk, Dr Bolton-Maggs stated:[144]

> "*I cannot now recall specific dates, however I think that testing for HTLV-3 became available from Richard Tedder's laboratory in 1984 so we would have been able to test for evidence of infection when this test became available. At this time it was not known what positive test results meant in terms of risk of developing illness in the patient*."

47. Furthermore:[145]

> "*I cannot recall specifics but the general approach would have been, do not give treatment unless indicated, use desmopressin where possible, try to use NHS rather than commercial concentrate and then heat-treated product as soon as it became available*."

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[142] WITN4160001 para 29.1
[143] WITN4160001 para 30.1
[144] WITN4160001 para 31.1
[145] WITN4160001 para 32.1

48. And:[146]

> "*These would have been used as the alternatives were less effective for bleeding complications. As far as I recall Haemophilia A patients were not reverted to cryoprecipitate. I do not remember what was decided for children as I was not generally treating children at UCH. It should not be forgotten that the reason for treating these patients was that they were at a very real risk of death and serious complications from bleeding had they not been treated.*"

49. Dr Bolton-Maggs could not provide any specific detail of what information was provided to patients about the risks of hepatitis and HIV.[147] She later referred to general principles:[148]

> "*General principles: I always aimed to keep patients and their families informed about the benefits and risks of treatment. This would have been verbal and age appropriate, and this would usually [be] backed up with written material.*"

50. She added that:[149]

> *"Alternatives would have been discussed where appropriate, such as the use of desmopressin. However, early adequate factor replacement was the only effective treatment for bleeding episodes in severe haemophilia."*

51. Dr Bolton-Maggs could not recall if patients were treated with cryoprecipitate in response to the risk of infection.[150] She considered that decisions and actions taken in response to the risks were appropriate:[151]

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[146] WITN4160001 para 33.1
[147] WITN4160001 para 37
[148] WITN4160001 para 51.1
[149] WITN4160001 para 52.1
[150] WITN4160001 para 46.1
[151] WITN4160001 para 47.1

"*I believe that the actions taken at UCH were appropriate. We kept updated with developments in viral safety and chose the most appropriate treatment that we could.*"

Testing patients for HTLVIII and informing them of diagnosis

52. Dr Bolton-Maggs stated that testing for HIV "*became available at UCH in about 1984 by Richard Tedder's laboratory but this was not a generally available test*".[152] Dr Bolton-Maggs could not remember the details of discussing AIDS with any patients, but set out the principle:[153]

> "*UCH – I do not remember the details, but the principle would have been to give as much information as we had at the time, and to update this as new understanding came.*"

53. Regarding the information that would have been provided about a positive diagnosis, Dr Bolton-Maggs said:[154]

> "*UCH – we had very little knowledge at the time what the result meant other than that the patient had been exposed to HIV. It was not at all clear what would happen as this was a new disease. We did not know how many would become severely immunosuppressed nor how many would die.*"

54. Dr Bolton-Maggs stated that "*Pre-test counselling would have been done by the doctors looking after the patients*".[155] She did not recall any other specific arrangements. She added that, "*At UCH the patients would have been told in person*".[156] She did not remember UCH's policy regarding disclosure to children or any particular policy relating to family members at UCH, although she thought they offered testing to partners if so desired.[157]

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[152] WITN4160001 para 55.1
[153] WITN4160001 para 54.1
[154] WITN4160001 para 58.1
[155] WITN4160001 para 56.1
[156] WITN4160001 para 57.1
[157] WITN4160001 para 60.1 and 61.1

Numbers infected with HIV

55. Dr Bolton-Maggs did not have any information about the numbers of infected patients at UCH.[158]

56. Provisional data received by the Inquiry from UKHCDO suggests that 5 patients tested positive for HIV: 1 patient is recorded as positive in 1982 (presumably reflecting the later testing of a 1982 stored sera sample), 1 patient tested positive in 1984, and 3 patients tested positive in 1985.[159]

Testing for HCV

57. Dr Bolton-Maggs stated that "*Testing for HCV became available in 1991 or 1992*",[160] by which time Dr Bolton-Maggs was working at Alder Hey Hospital. There is limited information available about the arrangements for testing for HCV at UCH and the numbers of patients infected with hepatitis at UCH.

Treatment arrangements for HIV and HCV patients

58. Dr Bolton-Maggs did not recall how patients with HIV or HCV were treated at UCH.[161] As far as she could recall, Dr Bolton-Maggs stated that "*any patients infected with NANB hepatitis would have been regularly reviewed with monitoring of their liver function tests*".[162]

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[158] WITN4160001 para 67.1
[159] INQY0000250
[160] WITN4160001 para 73.1
[161] WITN4160001 para 96.1 and 98.1
[162] WITN4160001 para 98.4

Inquiry Counsel Team

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