

SMALLER HAEMOPHILIA CENTRES

CHERTSEY HAEMOPHILIA CENTRE

The Centre

1. The Haemophilia Centre at St Peter's Hospital, Chertsey was designated as centre number 125.¹ It was part of the St Thomas' Hospital Supraregion of haemophilia centres.² Dr Vaughan Jones was Director of the Centre from at least 1977 to the end of the 1980s.³ Dr Anne Miller appears to have been co-director in 1986-1987.⁴

Number of patients treated

2. The available annual returns record the following patient numbers to 1985:
 - a. In 1978 the Centre treated 5 haemophilia A patients, 1 von Willebrand's disease patient, 1 haemophilia B patient, and 1 haemophilia B carrier.⁵
 - b. In 1979 the Centre treated 6 haemophilia A patients, 4 von Willebrand's disease patients, 2 haemophilia B patients and 1 haemophilia B carrier.⁶
 - c. In 1980 the Centre treated 7 haemophilia A patients, 1 von Willebrand's disease patient and 1 haemophilia B patient.⁷
 - d. In 1981 the Centre treated 7 haemophilia A patients, 1 von Willebrand's disease patient and 1 haemophilia B patient.⁸
 - e. In 1982 the Centre treated 6 haemophilia A patients, 1 haemophilia A carrier, 2 von Willebrand's disease patients, 1 haemophilia B patient and 1 haemophilia B carrier.⁹

¹ WITN3826016

² HCDO0000138_012

³ See BPLL0004826 and the documents referred to below.

⁴ HCDO0000309_002 and HCDO0002081

⁵ HCDO0001246

⁶ HCDO0001315

⁷ HCDO0001411

⁸ HCDO0001509

⁹ HCDO0001611

- f. In 1983 the Centre treated 5 haemophilia A patients, 3 von Willebrand's disease patients and 1 haemophilia B patient.¹⁰
- g. In 1984 the Centre treated 4 haemophilia A patients, 4 von Willebrand's disease patients, 1 haemophilia B patient and 2 haemophilia B carriers.¹¹
- h. In 1985 the Centre treated 4 haemophilia A patients, 4 von Willebrand's disease patients and 1 haemophilia B patient.¹²

Blood product usage

- 3. In 1978 the Centre treated its patients as follows:¹³
 - a. Haemophilia A patients were treated with NHS concentrate (25,940 units), cryoprecipitate (23,240 units) and commercial concentrate (Hemofil) (14,460 units).
 - b. The von Willebrand's disease patient was treated with NHS concentrate.
- 4. In 1979 the Centre treated its patients as follows:¹⁴
 - a. Haemophilia A patients were treated with commercial concentrate (Hemofil) (19,800 units) and NHS concentrate (19,000 units).
 - b. Von Willebrand's disease patients were treated with cryoprecipitate and NHS concentrate.
- 5. In 1980 the Centre treated its patients as follows:¹⁵
 - a. Haemophilia A patients were treated with NHS concentrate (49 bottles in hospital and 77 bottles for home treatment), commercial concentrate (Hemofil) (6 bottles in hospital and 120 bottles at home), and cryoprecipitate (83 bags in hospital). The return included the following comment: "*The large amount of Hemofil is because one patient is allergic to NHS VIII*".

¹⁰ HCDO0001708

¹¹ HCDO0001803

¹² HCDO0001895

¹³ HCDO0001246

¹⁴ HCDO0001315

¹⁵ HCDO0001411

- b. The von Willebrand's disease patient was treated with NHS concentrate in hospital.
- 6. In 1981 the Centre treated its patients as follows:¹⁶
 - a. Haemophilia A patients were treated with NHS concentrate (27,750 units in hospital and 8,750 units at home), commercial concentrate (Hemofil) (2,500 units in hospital and 31,500 units at home), and cryoprecipitate (6 bags in hospital).
 - b. The von Willebrand's disease patient was treated with NHS concentrate in hospital.
- 7. In 1982 the Centre treated its patients as follows:¹⁷
 - a. Haemophilia A patients were treated with NHS concentrate (11,295 units in hospital and 54,525 units at home).
 - b. The haemophilia A carrier was treated with NHS concentrate in hospital.
 - c. Von Willebrand's disease patients were treated with commercial concentrate (Hemofil), NHS concentrate, cryoprecipitate and plasma in hospital.
- 8. In 1983 the Centre treated its patients as follows:¹⁸
 - a. Haemophilia A patients were treated with NHS concentrate (10,840 units in hospital and 28,550 units at home) and commercial concentrate (Factorate) (10,175 units in hospital and 9,900 units at home).
 - b. Von Willebrand's disease patients were treated with cryoprecipitate and NHS concentrate in hospital.
- 9. In 1984 the Centre treated its patients as follows:¹⁹
 - a. Haemophilia A patients were treated with NHS concentrate (20,720 units, of which 8,535 were in hospital and 12,185 were at home) and commercial

¹⁶ HCDO0001509

¹⁷ HCDO0001611

¹⁸ HCDO0001708

¹⁹ HCDO0001803

concentrate (Factorate) (1,315 units, of which 275 units were in hospital and 1,040 at home).

- b. Von Willebrand's disease patients were treated with NHS concentrate and cryoprecipitate.

10. In 1985 the Centre treated its patients as follows:²⁰

- a. Haemophilia A patients were treated with commercial concentrate (Factorate) (13,400 units at home), NHS concentrate (2,700 units at home), cryoprecipitate (10 bags in hospital) and DDAVP.
- b. Von Willebrand's disease patients were treated with cryoprecipitate in hospital and at home and with DDAVP in hospital.

11. Throughout 1978-1985, haemophilia B patients and carriers were treated with NHS concentrate, both in hospital and at home.²¹

Treatment policies

12. Around September 1977, Professor Ingram at St Thomas' circulated a proposal for the distribution of NHS freeze-dried factor VIII concentrate (referred to as Elstree Haemophilic Factor, "EHF") to directors of haemophilia centres and associate centres in the South East and South West Thames regions, including Dr Vaughan Jones at the Chertsey Centre.²² In light of its limited availability, Professor Ingram's proposals included that EHF be used as a priority for home treatment and for major emergencies, and that cryoprecipitate should be used for routine treatments. He enclosed a proposed scheme for monthly distribution from the Tooting Regional Transfusion Centre, based on the number of patients on home treatment or who should be on home treatment. This recorded that the Chertsey Centre had 1 patient on and 3 patients to go on home treatment.

²⁰ HCDO0001895

²¹ HCDO0001246; HCDO0001315; HCDO0001411; HCDO0001509; HCDO0001611; HCDO0001708; HCDO0001803; HCDO0001895

²² CBLA0000704

13. Professor Ingram described this distribution scheme, which appears to have been implemented, in a 9 February 1978 letter to Dr Maycock.²³ He asked whether anything could be done to increase NHS production and commented: *“Since we already distribute nearly all our monthly allocation from the BPL, it looks as though more and more commercial material will have to be bought to satisfy our demands for home treatment alone, let alone our needs for surgery and patients with antibodies”*.

14. A letter from Dr Vaughan Jones to Professor Ingram dated 6 January 1978 suggested that a patient with mild haemophilia A should be provided with concentrate for home treatment:²⁴

“Although his bleeds are infrequent I have suggested that we should give him a small supply of freeze dried Factor VIII and this morning explained to him how this should be given. ... if he were able to give himself treatment at an early stage of a bleed such as the recent one the saving in work time lost and hospital bed occupancy would be very large”.

15. On 6 February 1985, Dr Vaughan Jones wrote to Dr Snape at BPL to apply for intermediate purity, heat-treated Factor VIII for two patients.²⁵ He indicated a preference to defer an application for heat-treated material for two child patients until BPL’s 8Y concentrate was available. One of those patients was an untreated infant and the other had previously been treated with cryoprecipitate.

Knowledge of risk of hepatitis and HTLV-III/AIDS

16. UKHCDO minutes show that Dr Vaughan Jones attended UKHCDO meetings on 13 November 1978²⁶, 17 October 1983²⁷, 21 October 1985²⁸, 17 March 1986²⁹, 29 September 1988³⁰ and 9 October 1989.³¹ Dr Miller attended the 9 October 1986 meeting.³² It may be reasonable to assume that, as Director of the Chertsey Centre, Dr

²³ CBLA0000728

²⁴ ARCH0003230

²⁵ CBLA0002023

²⁶ HSOC0010549

²⁷ PRSE0004440

²⁸ PRSE0001638

²⁹ PRSE0001688

³⁰ BART0002329

³¹ HCDO0000015_035

³² PRSE0004317

Vaughan Jones would have received copies of the reports circulated for, and the minutes of, UKHCDO meetings that he did not attend.

17. In February 1976, the Centre was made aware of a young haemophilia patient who was a student at Treloar College and had been infected with hepatitis.³³ The Centre provided the College with a list of the concentrate and cryoprecipitate the patient had received in the previous 6 months.³⁴

18. In May 1979, Miss Spooner (at the Oxford Haemophilia Centre) wrote to Dr Vaughan Jones about a patient who she understood had developed hepatitis.³⁵ Dr Vaughan Jones replied that that patient had reverted to the care of another haemophilia centre.³⁶

19. On 27 September 1985, Dr Vaughan Jones wrote to the Medical Director at Armour Pharmaceutical to ask whether company's heat treatment method was "*expected to kill Hepatitis virus of the 'B', 'A' and 'non A' 'non B' varieties*".³⁷ He noted that "*the new NHS VIII Y is thought to be likely to be free of the risk of hepatitis by dint of the long heat treatment which is employed in this preparation although time will tell*". He went on to comment:

"You may know that there is a good deal of sample testing associated with the use of the NHS preparation and in particular in children the actual taking of these rather numerous samples is scarcely ethical unless the preparation of a better alternative than the other ones and it's in the best interests of the child to receive it. This is why I am asking for this information."

20. In a 1 October 1985 response, Dr Peter Harris wrote that "*[s]ome details of the methodology are as yet unknown to me as are some of the virus kill study results.*"³⁸ He added that he would be visiting "*research colleagues in the United States*" the following week, following which he would be in a position to respond to Dr Vaughan Jones's query.

³³ TREL0000070_062

³⁴ TREL0000070_061

³⁵ HCDO0000255_052

³⁶ HCDO0000255_051

³⁷ ARMO0000431

³⁸ ARMO0000433

21. Dr Vaughan Jones's letter was referred to in a 2 October 1985 internal Armour memo, addressed to Dr Harris and others, on the effectiveness of its heat-treatment method.³⁹ The memo recorded that the company's "*clinical trial on heat treated Factorate showed 3 out of 3 cases with clinical non-A, non-B Hepatitis*", and that it had received "*similar reports following commercial use of the product*". Having noted Dr Vaughan Jones's recent letter, the memo commented that the company had "*clean chimp data, but the clinical data above is discouraging*".

Testing for HIV/HCV and numbers of patients infected

22. UKHCDO data available to the Inquiry suggests that no patients were identified as having been infected with HIV at the Centre between 1985 and 1987.⁴⁰
23. An Inquiry witness with von Willebrand's disease, who was treated at St Thomas' in the late 1960s and 1970s and the Chertsey Centre in the early 1980s and was infected with HCV, was monitored for HIV without her knowledge at the Centre.⁴¹ Dr Vaughan Jones described this monitoring in a 15 May 1984 letter to the patient's GP, in which he recorded that the patient had been treated with "*large quantities of cryoprecipitate and Factor VIII concentrates*" in 1982 in response to haemorrhaging arising from a pregnancy termination.⁴² Dr Vaughan's description of the Centre's approach to monitoring patients for HIV merits being set out in detail:

"You will be aware of all the recent fuss about AIDS. It appears that among the materials she was given were bottles of VIII concentrate from the same batch as that which has been one of a number of a number of batches given to one of the English cases of AIDS in haemophiliacs. All haemophilia centre [heads?] and directors have therefore been asked to carry out [illegible] clinical haematological and virological tests at regular intervals on all such cases without telling them there is any suggestion that they might catch AIDS. I wrote a fairly heated letter to the relevant virologist (who is [GRO-A]'s brother) pointing out the alarm which would be caused by doing this to a patient who one hasn't seen for about a couple of years. The chance of

³⁹ ARMO0000434

⁴⁰ WITN3826020

⁴¹ WITN1026001

⁴² WITN1026003

catching the infection are in the order of one in a thousand and as there is no treatment it didn't seem to me to be ethical to make the approach.

His reply was "however if she is in good health and does not require regular blood therapy, perhaps the best way of keeping an eye on her clinical state would be to write to her GP and ask him to notify you should she present with any illness for which there is no obvious cause.""

24. Dr Vaughan Jones added that “[t]hey envisaged follow-up for four years of which two have elapsed”, and suggested symptoms for the GP to monitor over the subsequent two years.

25. Dr Vaughan Jones has provided an Inquiry statement addressing this issue, in which he states: *“In order to avoid needless distress, it was thought wise not to inform patients that they were being screened for HIV as the vast majority would be found negative. I agreed with the idea behind it but wasn't altogether happy about the secrecy.”*⁴³ In relation to the von Willebrand's patient, his evidence is that *“I did not inform her about the screening as far as I can remember. My feeling was that she was much better off not knowing about it”*.

26. The patient's statement also explains that, around 1986, she was asked to take an HIV test, which she agreed to and was carried out by Dr Vaughan Jones.⁴⁴ She further describes Dr Vaughan Jones recommending that she be tested for HCV in 1990. In a 3 January 1990 letter informing her of the result, he wrote:⁴⁵

“Your serum went to Colindale for testing with the new reagent to detect antibodies to the Hepatitis Virus C and antibodies were found in your serum so your so-called non-A non-B Hepatitis was due to Hepatitis Virus C.”

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November 2022

⁴³ WITN5504001 para 5

⁴⁴ WITN1026001

⁴⁵ WITN1026004