

SMALLER HAEMOPHILIA CENTRES

WORTHING HAEMOPHILIA CENTRE

The Centre and relationship with other Haemophilia Centres

1. The Haemophilia Centre at Worthing Hospital was designated as centre number 132. The Centre's Director in 1977 and 1978 was Dr K Rodan, who was succeeded by Dr Colin Rist for the remainder of the 1970s and 1980s.¹
2. The Worthing Centre was part of the St. Thomas' Hospital Supraregion of haemophilia centres.² Documents referred to below suggest it had a relationship with the St Thomas' Centre.

Number of patients treated

3. The available annual returns record the following patient numbers to 1985:
 - a. 1977: The Centre treated 5 haemophilia A patients and 1 haemophilia B patient.³
 - b. 1979: The Centre treated 8 haemophilia A patients and 1 patient with Von Willebrand's disease.⁴
 - c. 1980: The Centre treated 5 haemophilia A patients, 1 haemophilia B patient and 1 Von Willebrand's disease patient.⁵
 - d. 1981: The Centre treated 3 haemophilia A patients, 2 haemophilia B patients and 3 Von Willebrand's disease patients.⁶
 - e. 1982: The Centre treated 5 haemophilia A patients, 4 haemophilia B patients, 1 haemophilia A carrier and 3 Von Willebrand's disease patients.⁷

¹ See the annual returns referred to below, as well as HCDO0002062, HCDO0002151, HCDO0002245 and HCDO0002336.

² HCDO0000138_012

³ HCDO0001222

⁴ HCDO0001386

⁵ HCDO0001485

⁶ HCDO0001588

⁷ HCDO0001684

- f. 1983: The Centre treated 5 haemophilia A patients, 3 haemophilia B patients and 2 Von Willebrand's disease patients.⁸
- g. 1984: The Centre treated 8 haemophilia A patients, 4 haemophilia B patients and 1 Von Willebrand's disease patient.⁹
- h. 1985: The Centre treated 7 haemophilia A patients, 2 haemophilia B patients, and 1 Von Willebrand's disease patient.¹⁰

Blood product usage

- 4. In 1977, the Centre treated its haemophilia A patients with cryoprecipitate (57,050 units) and commercial concentrate (Hemofil) (4,800 units).¹¹
- 5. In 1979, the Centre treated its patients as follows:¹²
 - a. Haemophilia A patients were treated with cryoprecipitate (34,860 units), NHS concentrate (30,600 units) and commercial concentrate (Factorate and Kryobulin) (3,870 units).
 - b. The patient with Von Willebrand's disease was treated with cryoprecipitate and plasma.
- 6. In 1980, the Centre treated its patients as follows:¹³
 - a. Haemophilia A patients were treated with cryoprecipitate (359 bags in hospital), NHS concentrate (111 bottles at home) and commercial concentrate (Kryobulin) (6 bottles in hospital and 14 at home).
 - b. The patient with Factor VIII antibodies was treated with cryoprecipitate, NHS concentrate and commercial concentrate (Kryobulin) in hospital.

⁸ HCDO0001780. A 13 March 1984 letter, found alongside the return, explained that the Centre had mistakenly suggested that a haemophilia A carrier had been treated in 1983.

⁹ HCDO0001873

¹⁰ HCDO0001969

¹¹ HCDO0001222

¹² HCDO0001386

¹³ HCDO0001485

- c. The patient with Von Willebrand's disease was treated with cryoprecipitate and NHS concentrates in hospital.

7. In 1981, the Centre treated its patients as follows:¹⁴

- a. Haemophilia A patients were treated with cryoprecipitate (385 bags), NHS concentrate (35,250 units, of which 7,750 units were in hospital and 27,500 were at home) and commercial concentrate (Hemofil and Immuno) (10,000 units, of which 7,750 were in hospital and 2,250 were at home).
- b. The haemophilia A patient with antibodies was treated with NHS concentrate and commercial concentrate in hospital.
- c. Von Willebrand's disease patients were treated with cryoprecipitate and commercial concentrate in hospital.

8. In 1982, the Centre treated its patients as follows:¹⁵

- a. Haemophilia A patients were treated with NHS concentrate (29,500 units, of which 500 units were in hospital and 29,000 at home), cryoprecipitate (19,040 units, of which 3,500 were in hospital and 15,540 at home) commercial concentrate (Hemofil and Kryobulin) (12,000 units, of which 1,750 units were in hospital and 10,250 at home).
- b. The haemophilia A carrier was treated with cryoprecipitate in hospital.
- c. Von Willebrand's disease patients were treated with cryoprecipitate, commercial concentrate, NHS concentrate and plasma.

9. In 1983, the Centre treated its patients as follows:¹⁶

- a. Haemophilia A patients were treated with were treated with NHS concentrate (the unit numbers are unclear but would appear to be 65,250 units in hospital and 54,000 units at home) and cryoprecipitate (34 bags, of which 10 bags were in hospital and 24 bags at home).

¹⁴ HCDO0001588

¹⁵ HCDO0001684

¹⁶ HCDO0001780

- b. Von Willebrand's disease patients were treated with commercial concentrate (Hemofil and Factorate), NHS concentrate and cryoprecipitate in hospital.
10. In 1984, the Centre treated its haemophilia A patients with NHS concentrate (64,860 units, of which 7,050 units were in hospital and 57,810 were at home) and heat-treated concentrate (2 bottles in hospital, with the manufacturer not specified).¹⁷
11. In 1985, the Centre treated its patients as follows:¹⁸
- a. Haemophilia A patients were treated with NHS concentrate (126,750 units, of which 72,750 units were in hospital and 54,000 units at home).
- b. The Von Willebrand's disease patient was treated with cryoprecipitate in hospital.
12. Throughout the period 1977-1985, the Centre treated its haemophilia B patients with NHS concentrate, both in hospital and at home.
13. It appears that the Centre did not initially respond to a request from BPL for details of patients it wished to treat with heat-treated Factor VIII concentrate, and that this may have delayed the Centre's receipt of such material from BPL. Dr Rist wrote as follows in a September 1985 letter to Dr Snape at BPL:¹⁹

“We seem to have got ourselves into a muddle over Factor VIII supplies to Worthing. I think this arose when we received the questionnaire regarding heat treated material which we did not feel that we would have time to take part in. Unfortunately, I did not appreciate that because of this our supplies of Factor VIII would dry completely. I am therefore sending you a list of our haemophiliac patients so that we can continue to treat them with NHS material.”

¹⁷ HCDO0001873

¹⁸ HCDO0001969

¹⁹ BPLL0010508

14. There is, however, evidence that the Centre obtained heat-treated Factor VIII concentrate from St Thomas' Hospital. On 11 September 1985, Dr Roques (a consultant haematologist at the Centre) wrote to Dr Savidge to return 70,000 units of the 100,000 units of heat-treated concentrate Dr Savidge had sent to cover a patient's operation.²⁰

Knowledge of risk of hepatitis and HTLV-III/AIDS

15. Dr Rodan is not recorded as having any attended any UKHCDO meetings. UKHCDO minutes show that, in the 1970s and 1980s, Dr Rist attended meetings of haemophilia centre directors on 21 November 1979²¹, 21 October 1985²², 25 September 1987²³ and 9 October 1989.²⁴

16. It may be reasonable to assume that, as Centre Directors, Dr Rodan and Dr Rist would have received copies of the reports circulated for, and the minutes of, any such UKHCDO meetings at which they were not in attendance.

17. In a 2 February 1985 letter to Dr Savidge, reporting the outcome of a recent routine appointment with a patient, Dr Roques explained that the Centre had taken blood from the patient for liver function tests and Australia antigen (i.e. hepatitis B), as well as noting that the patient was expecting an appointment with Dr Savidge to discuss "*the material he is to use in the future as he and we are naturally a little bit concerned about the AIDS scare*".²⁵

Testing for HIV/HCV and numbers of patients infected

18. UKHCDO data available to the Inquiry suggests that 1 patient in 1984 and 1 patient in 1985 were identified at the Centre as having been infected with HIV.²⁶

²⁰ WITN1230005

²¹ CBLA0001028

²² PRSE0001638

²³ HCDO0000485

²⁴ HCDO0000015_035

²⁵ WITN1230005

²⁶ WITN3826020

19. An Inquiry witness with haemophilia A, who was infected with HIV and HCV, has exhibited a number of documents relevant to the Centre’s approach to HIV testing.²⁷ A Public Health Laboratory Service result records that the patient tested positive in August 1985, when he was around 19 years old.²⁸ In an 11 September 1985 letter to Dr Savidge at St Thomas’, Dr Roques explained that the Centre had received the positive test result from PHLS in Colindale, that the patient’s mother had been informed and that he had seen Dr Rist.²⁹ Dr Roques also noted that the patient and Dr Savidge might wish to see each other.
20. Further documents exhibited by the witness suggest that his GP was not informed of his positive antibody result until December 1986. In a 10 December 1986 letter to the GP, Dr Rist explained that the witness “*and his mother had their HIV status tested in 1985 as part of a confidential national survey of all haemophiliacs*”³⁰ He added that “[*t*]his is a difficult ethical area and I have not routinely passed the information on”, but in view of the GP’s interest he had “*obtained the verbal consent*” of the patient’s mother and was providing the results. Dr Rist further explained that the witness had “*already had counselling from me and at St Thomas’ Hospital where there is a professional psychologist dealing with haemophiliac patients*”. In a 12 December 1986 response, the patient’s GP was highly critical of the length of time that had passed before he was informed of the test result.³¹

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November 2022

²⁷ WITN1230001

²⁸ WITN1230005 p.5

²⁹ WITN1230005 p.3

³⁰ WITN1230008

³¹ WITN1230005 p.4