

SMALLER HAEMOPHILIA CENTRES

CENTRES IN SUSSEX: Hastings, Brighton, Eastbourne, Chichester

ROYAL EAST SUSSEX HOSPITAL, HASTINGS

The Centre

1. The Haemophilia Centre at the Royal East Sussex Hospital (“the Hastings Centre”) was designated as centre number 117.¹ The Director during the 1970s to 1990 was Dr Kathleen (Kate) M Harrison,² and during the 1990s was Dr Judy Beard.³
2. The Hastings Centre was part of the St Thomas’ Hospital Supraregion,⁴ and received blood products from the South London Transfusion Centre.⁵ It was an Associate Centre in the South East Thames Health Regional Health Authority.⁶
3. The Royal East Sussex Hospital closed in 1992,⁷ and Conquest Hospital became the location of Centre 117.⁸

Relationship with other Haemophilia Centres

4. The Hastings Centre had links with a number of London hospitals. In 1985, Dr Harrison referred to “*shared*” patients that were under her care but also attended hospitals such as St Thomas’ Hospital, Royal Free Hospital, and Great Ormond Street Hospital. The arrangements appear to differ for each patient, with some patients receiving their treatment from both Centres.⁹

Number of patients treated

5. The available annual returns to 1985 record the following patient numbers:

¹ HCDO0000119_138

² BPLL0010509; HCDO0000138_007; CBLA0002121

³ HCDO0002371

⁴ CBLA0000699

⁵ CBLA0002121

⁶ CBLA0000728; DHSC0002347_015, p. 23

⁷ <https://www.esht.nhs.uk/history/the-nhs-at-70-years-old/nhs-70th-royal-east-sussex-hospital/>

⁸ HCDO0000124_043

⁹ CBLA0002103; CBLA0002098

- a. 1976: the Hastings Centre treated 1 haemophilia A patient.¹⁰
- b. 1977: the Hastings Centre treated 3 haemophilia A patients, 1 haemophilia B patient, and, 1 haemophilia A carrier.¹¹
- c. 1978: the Hastings Centre treated 5 haemophilia A patients, 2 haemophilia B patients and 1 Von Willebrand's disease patient.¹²
- d. 1979: the Hastings Centre treated 5 haemophilia A patients, 1 haemophilia B patient, and 1 haemophilia A carrier.¹³
- e. 1980: the Hastings Centre treated 5 haemophilia A patients and 1 haemophilia A carrier.¹⁴
- f. 1981: the Hastings Centre treated 3 haemophilia A patients.¹⁵
- g. 1982: the Hastings Centre treated 4 haemophilia A patients, and 1 haemophilia B patient.¹⁶
- h. 1983: the Hastings Centre treated 5 haemophilia A patients, and 1 haemophilia A carrier.¹⁷
- i. 1984: the Hastings Centre treated 6 haemophilia A patients, and 1 haemophilia B patient.¹⁸
- j. 1985: the Hastings Centre treated 4 haemophilia A patients, and 2 Von Willebrand's disease patients.¹⁹

6. Throughout the period 1976 to 1985, the Hastings Centre's patients included children.

¹⁰ HCDO0000060_002

¹¹ HCDO0001165

¹² HCDO0001262

¹³ HCDO0001331

¹⁴ HCDO0001426

¹⁵ HCDO0001527

¹⁶ HCDO0001627

¹⁷ HCDO0001726

¹⁸ HCDO0001818

¹⁹ HCDO0001912

Blood product usage

7. In 1976, the Hastings Centre treated its haemophilia A patient with cryoprecipitate only (5,320 units²⁰).²¹
8. In 1977, the Hastings Centre treated its patients as follows:²²
 - a. Haemophilia A patients were treated with cryoprecipitate (28,000 units), commercial concentrates (Kryobulin) (9,120 units), and NHS concentrates (2,180 units).
 - b. The patient with Factor VIII inhibitors was treated with cryoprecipitate and commercial concentrate (Kryobulin).
 - c. The patient who was a haemophilia A carrier was treated with cryoprecipitate.
9. In 1978, the Hastings Centre treated its patients as follows:²³
 - a. Haemophilia A patients with NHS concentrates (23,845 units), NHS concentrates (16,030 units) and commercial concentrates (Factorate) (486 units).
 - b. The patient with Factor VIII inhibitors was treated with NHS concentrate.
 - c. The patient with Von Willebrand's disease was treated with cryoprecipitate.
10. In 1979, the Hastings Centre treated its patients as follows:²⁴
 - a. Haemophilia A patients were treated with NHS concentrates (25,180 units), commercial concentrates (Factorate) (16,271 units), and cryoprecipitate (14,140 units).
 - b. The patient with Factor VIII inhibitors was treated with NHS concentrate.

²⁰ The annual returns list 76 bags. The unit amount has been calculated at 70 units per bag based on the annual returns from the following year.

²¹ HCDO0000060_002

²² HCDO0001165

²³ HCDO0001262

²⁴ HCDO0001331

- c. The patient who was a haemophilia A carrier was treated with NHS concentrate.

11. In 1980, the Hastings Centre treated its patients as follows:²⁵

- a. Haemophilia A patients were treated with cryoprecipitate (46,060 units)²⁶, NHS concentrates (32,375 units), and commercial concentrates (Factorate) (7,660 units).
- b. The patient who was a haemophilia A carrier was treated with NHS concentrate.

12. In 1981, the Hastings Centre treated its haemophilia A patients with NHS concentrate (37,980 units), cryoprecipitate (21,280 units), and commercial concentrates (Factorate) (2,750 units).²⁷

13. In 1982, the Hastings Centre treated its haemophilia A patients with NHS concentrates (25,770 units), cryoprecipitate (10,990 units) and commercial concentrates (Factorate) (9,720 units).²⁸

14. In 1983, the Hastings Centre treated its patients as follows:²⁹

- a. Haemophilia A patients were treated with NHS concentrates (39,755 units), cryoprecipitate (11,690 units), and commercial concentrates (Factorate) (980 units).
- b. The patient with Factor VIII inhibitors was treated with NHS concentrate and commercial concentrate (Factorate).

15. In 1984, the Hastings Centre treated its patients as follows:³⁰

²⁵ HCDO0001426

²⁶ The annual returns list 658 bags. The unit amount has been calculated at 70 units per bag based on the annual returns from the surrounding years.

²⁷ HCDO0001527

²⁸ HCDO0001627

²⁹ HCDO0001726

³⁰ HCDO0001818

- a. Haemophilia A patients were treated with NHS concentrates (64,805 units), commercial concentrates (Factorate) (4,320 units) and cryoprecipitate (2,380 units).
- b. The patient with Factor VIII inhibitors was treated with NHS concentrate and commercial concentrate (Factorate).

16. In 1985, the Hastings Centre treated its patients as follows:³¹

- a. Haemophilia A patients were treated with commercial concentrates (Profilate and Immuno Partial Prothrombin Complex) (43,120 units), NHS concentrates (19,740 units), and cryoprecipitate (420 units).
- b. The patients with Von Willebrand's disease were treated with cryoprecipitate.
- c. The patient with Factor VIII inhibitors was treated with NHS concentrate and Factor IX commercial concentrate (Immuno Partial Prothrombin Complex).³²

17. Throughout the period 1976-1985, the Hastings Centre treated its haemophilia B patients with NHS Factor IX concentrates. In 1978, the Hastings Centre used plasma and NHS Factor IX concentrates. In 1982, the Centre used NHS Factor VIII and Factor IX concentrates.

18. In January 1985, Dr Harrison stated she had been advised by the UK Haemophilia Reference Centre Directors that patients should receive heat-treated Factor VIII *"to minimise the possibility of getting AIDS."* Dr Harrison stated that she had adequate supplies of NHS Factor VIII, but would have *"difficulty obtaining the money to buy in commercial heat-treated Factor VIII until such time as suitable material is available from the Blood Products Laboratory."*³³

19. In March 1985, Dr Harrison requested heated Factor VIII concentrate for several patients. She stated that she had a *"problem"* with some patients as they also attended other Centres and that *"it is difficult for me to know whether to fill in the forms as*

³¹ HCDO0001912

³² The Centre's annual returns from 1986-1990 are at: HCDO0000283_004, HCDO0002095, HCDO0002188, HCDO0002280 and HCDO0002371.

³³ WITN0906003

*those patients requiring continuous treatment are receiving heat treated commercial factor VIII at other hospitals and I feel, therefore, may not be eligible for the NHS material later on.*³⁴ She wrote to Dr K Roger at the South London Transfusion Centre, and said she would like to be able to offer BPL heat-treated Factor VIII concentrate, but faced the above issue.³⁵ Dr Roger responded that the control of the BPL product is *“entirely in the hands of the BPL. I cannot agree to let you have any of this material without their authority.”*³⁶ He also stated that the sharing of patient care should not matter as long as the BPL reporting requirements can be complied with.

Treatment policies

20. In September 1977, Professor Ingram of St Thomas' Hospital wrote about the distribution of NHS freeze-dried factor VIII concentrate to the South East and South West Thames Regions. He acknowledged that the NHS could not produce enough material for requirements, and suggested that NHS concentrates should be used for home treatment and major emergencies at centres. Cryoprecipitate was to be used for routine treatments at centres, and any shortfall of the above should be met by commercial concentrates.³⁷

21. Distribution was to be based on the number of patients on home treatment at each centre, with each patient to be allocated 6 vials a month. The Hastings Centre reported 1 patient on home treatment as at September 1977 and was allocated 6 vials a month.³⁸ In February 1978, Professor Ingram reported to BPL on how their allocation was being used, and confirmed the suggested arrangements.³⁹

22. Dr Harrison attended a meeting of the South East Thames Regional Health Authority, Regional Haematology Speciality Sub-Committee held on 11 September 1986. The meeting referred to a previous meeting's minutes where Dr Savidge provided an update on the production of factor 8Y, and that St Thomas' would take little of the

³⁴ CBLA0002098

³⁵ CBLA0002103

³⁶ CBLA0002121

³⁷ CBLA0000704

³⁸ CBLA0000704

³⁹ CBLA0000728

supplies to ensure that the majority of NHS products were available to other units in the region. He was to meet with the Regional Supplies Officer and report back regarding BPL production capacity.⁴⁰

Knowledge of risk of hepatitis/AIDS and HTLV-III

23. UKHCDO minutes show that Dr Harrison did not attend any UKHCDO meetings of haemophilia centre directors while she was at the Hastings Centre, though she is recorded as having sent apologies for the 24 October 1977⁴¹ and 17 March 1986 meetings.⁴² However, it may be reasonable to assume that Dr Harrison, as Director of the Hastings Centre, was sent minutes of the meetings that she did not attend in person.

24. Dr Harrison was listed as a member of the British Society for Haematology for the Hastings Centre from 1979/80.⁴³ She had been a member for another hospital since at least 1967/1968,⁴⁴ and was listed as a member for the Department of Haematology at Royal East Sussex Hospital Hastings from 1975/76.⁴⁵

25. Royal East Sussex Hospital was one of 11 hospitals provided with diagnostic and reference services for markers of infection with hepatitis A and B through the WHO Collaborating Centre for Reference and Research on Viral Hepatitis. In the 1978-1979 Annual Report on the program to the Department of Health and Social Security, it was recommended that *“until blood donors can be specifically screened for the virus(es) of non-A, non-B hepatitis, it would seem wise to restrict the use of blood concentrates to life-threatening situations.”*⁴⁶ It is unclear whether the participating hospitals received a copy of this report, authored by A. J. Zuckerman.

26. In 1979, Dr Harrison tested a patient for Australia Antigen on the basis that he had received a large amount of blood products. The test was positive and she wrote, *“he has no symptoms and has never been jaundiced and the test was done as a routine*

⁴⁰ DHSC0041402_008

⁴¹ PRSE0001002

⁴² PRSE0001688

⁴³ BSHA0000114

⁴⁴ BSHA0000113

⁴⁵ BSHA0000138

⁴⁶ DHSC0046961_023

investigation because he had been transfused many times and had a large amount of blood products.”⁴⁷

Testing for HIV/HCV and numbers of patients infected

27. Provisional UKHCDO data available to the Inquiry suggests that 0 people were infected with HIV at the Hastings Centre.⁴⁸ However, it is possible that the patients “*shared*” with other centres were not included in the count of the Hastings Centre.

⁴⁷ HCDO0000257_096

⁴⁸ INQY0000250

ROYAL SUSSEX COUNTY HOSPITAL, BRIGHTON

The Centre

28. The Haemophilia Centre at the Royal Sussex County Hospital (“the Brighton Centre”) was designated as centre number 118.⁴⁹ The Director during the 1970s until December 1982 was Dr J F Horley.⁵⁰ Dr Morgenstern was locum Director prior to Dr Martin Kenny assuming the position in December 1983.⁵¹
29. The Royal Sussex County Hospital was receiving cryoprecipitate from the South London Transfusion Centre in 1973 but was not considered a haemophilia centre at this stage.⁵² The Brighton Centre was designated as a Haemophilia Centre in the mid-1970s as part of the St Thomas’ Supraregion.⁵³ By 1985, it was referred to as an Associate Centre and was within the South East Thames Regional Health Authority.⁵⁴

Relationship with other haemophilia centres

30. Much like the Hastings Centre, Brighton had patients that were co-registered at multiple Centres. One particular patient was registered in London, but would collect their regular treatments from Brighton.⁵⁵
31. The Brighton Centre also had a relationship with Lord Mayor Treloar College (“Treloar’s”). At least one patient attended Treloar’s for schooling, and during holiday periods was registered at both the Brighton Centre, and the Great Ormond Street Hospital.⁵⁶ Treloar’s believed that a “*normal school*” would be better for the child, however, his mother was “*very keen*” for him to remain at Treloar’s,⁵⁷ which he did until he completed his schooling. The Brighton Centre continued to treat him during the holidays throughout his schooling.

⁴⁹ HCDO0000119_138

⁵⁰ HCDO0000138_007, p. 6

⁵¹ HCDO0000200_007; OXUH0001891_003

⁵² DHSC0100026_178

⁵³ CBLA0000704; CBLA0000699

⁵⁴ DHSC0002347_015, p. 23

⁵⁵ WITN3094039

⁵⁶ TREL0000041_104; TREL0000041_102

⁵⁷ TREL0000041_125; TREL0000041_126; TREL0000041_044

Number of patients treated

32. The available annual returns to 1985 record the following patient numbers:

- a. 1976: the Brighton Centre treated 21 haemophilia A patients and 4 haemophilia B patients.⁵⁸
- b. 1977: the Brighton Centre treated 17 haemophilia A patients, and 1 haemophilia B patient.⁵⁹
- c. 1978: the Brighton Centre treated 19 haemophilia A patients, and 3 haemophilia B patients.⁶⁰
- d. 1979: the Brighton Centre treated 20 haemophilia A patients, and 3 haemophilia B patients.⁶¹
- e. 1980: the Brighton Centre treated 15 haemophilia A patients and 5 haemophilia B patients.⁶²
- f. 1981: the Brighton Centre treated 19 haemophilia A patients and 1 haemophilia B patient.⁶³
- g. 1982: the Brighton Centre treated 16 haemophilia A patients, 3 haemophilia B patients, and 1 Von Willebrand's disease patient.⁶⁴
- h. 1983: the Brighton Centre treated 15 haemophilia A patients, and 4 haemophilia B patients.⁶⁵
- i. 1984: the Brighton Centre treated 19 haemophilia A patients, 5 haemophilia B patients and 1 patient with a Factor XI deficiency.⁶⁶

⁵⁸ HCDO0001062

⁵⁹ HCDO0001142

⁶⁰ HCDO0001237

⁶¹ HCDO0001306

⁶² HCDO0001401

⁶³ HCDO0001499

⁶⁴ HCDO0001602

⁶⁵ HCDO0001698

⁶⁶ HCDO0001794

- j. 1985: the Brighton Centre treated 15 haemophilia A patients, 2 haemophilia B patients, and 1 Von Willebrand's disease patient.⁶⁷

33. Throughout the period 1976 to 1985, the Brighton Centre's patients included children.

Blood product usage

34. In 1976, the Brighton Centre treated its haemophilia A patients with cryoprecipitate (188,640 units) and NHS concentrates (2,100 units).⁶⁸

35. In 1977, the Brighton Centre treated its haemophilia A patients with cryoprecipitate (143,850 units), commercial concentrates (Koate and Hemofil) (52,670 units) and NHS concentrates (48,990 units).⁶⁹

36. In 1978, the Brighton Centre treated its haemophilia A patients with NHS concentrates (168,710 units), cryoprecipitate (90,020 units) and commercial concentrates (Factorate) (14,558 units).⁷⁰

37. In 1979, the Brighton Centre treated its patients as follows:⁷¹

- a. Haemophilia A patients were treated with NHS concentrates (156,100 units), cryoprecipitate (63,280 units) and commercial concentrates (Factorate) (10,440 units).
- b. The patient with Factor VIII inhibitors was treated with NHS concentrates.

38. In 1980, the Brighton Centre treated its patients as follows:⁷²

- a. Haemophilia A patients were treated with cryoprecipitate (42,420 units), NHS concentrates (469 bottles), and commercial concentrates (Factorate) (315 bottles).

⁶⁷ HCDO0001886

⁶⁸ HCDO0001062

⁶⁹ HCDO0001142

⁷⁰ HCDO0001237

⁷¹ HCDO0001306

⁷² HCDO0001401

- b. The patient with Factor VIII inhibitors was treated with NHS concentrates and commercial concentrates (Factorate).

39. In 1981, the Brighton Centre treated its patients as follows:⁷³

- a. Haemophilia A patients were treated with NHS concentrates (474,835 units), commercial concentrates (Factorate) (149,694 units), and cryoprecipitate (9,240 units).
- b. The patient with Factor VIII inhibitors was treated with NHS concentrates and commercial concentrates (Factorate).

40. In 1982, the Brighton Centre treated its patients as follows:⁷⁴

- a. Haemophilia A patients were treated with NHS concentrates (131,583 units) and commercial concentrates (Factorate) (100,032).
- b. The patient with Von Willebrand's disease was treated with NHS concentrates.

41. In 1983, the Brighton Centre treated its patients as follows:⁷⁵

- a. Haemophilia A patients were treated with NHS concentrates (158,620 units) and commercial concentrates (Factorate) (138,570 units).
- b. The patient with Factor VIII inhibitors was treated with NHS Factor IX and Autoplex.

42. In 1984, the Brighton Centre treated its patients as follows:⁷⁶

- a. Haemophilia A patients were treated with NHS concentrates (165,750 units), commercial concentrates (133,999 units) and cryoprecipitate (5250 units).
- b. The patient with Factor VIII inhibitors was treated with NHS Factor IX.
- c. The patient with Factor XI deficiency was treated with plasma.

⁷³ HCDO0001499

⁷⁴ HCDO0001602

⁷⁵ HCDO0001698

⁷⁶ HCDO0001794

43. In 1985, the Centre treated its patients as follows:⁷⁷

- a. Haemophilia A patients were treated with commercial concentrates (216,735 units), NHS concentrates (90,210 units) and cryoprecipitate (420 units).
- b. The patient with Factor VIII inhibitors was treated with commercial Factor IX (Profilnine) and FEIBA.
- c. The patient with Von Willebrand's disease was treated with DDAVP.⁷⁸

44. Throughout the period 1976-1985, the Brighton Centre treated its haemophilia B patients with NHS Factor IX concentrates. In 1977, the Centre used plasma. In 1984, the Centre also used Fresh Frozen Plasma, and in 1985 the Centre also used commercial Factor IX (Profilnine).

45. In 1975, prior to the Brighton Centre's designation as a Haemophilia Centre, Dr Maycock wrote to the Hospital and stated that the Blood Products Laboratory could not send concentrates at regular intervals, and that "*every effort will be made to help*" to send concentrate for two patients that were "*sensitive to cryoprecipitate.*"⁷⁹

46. In June 1985, Dr Kenny ordered heat-treated Factor VIII from Dr Snape for use with four patients.⁸⁰

Treatment policies

47. Please refer to paragraph 20 and 21 under Royal East Sussex Hospital, Hastings. Both Centres were part of the same Thames Region.⁸¹

48. The Brighton Centre reported 2 patients already on home treatment and a further to commence home treatment as at September 1977. The Brighton Centre was assigned 18 vials per month.⁸²

⁷⁷ HCDO0001886

⁷⁸ The Centre's annual returns for 1986-1990 are at HCDO0001982, HCDO0002075, HCDO0002164, HCDO0002258 and HCDO0002349.

⁷⁹ BPLL0003806

⁸⁰ CBLA0002198

⁸¹ CBLA0000704

⁸² CBLA0000704

49. Dr Kenny also attended the meeting of the Regional Haematology Speciality Sub-Committee referred to in paragraph 22 above.⁸³

Knowledge of risk of hepatitis/AIDS and HTLV-III

50. Both Dr Horley and Dr Kenny regularly attended UKHCDO meetings of haemophilia centre directors. UKHCDO minutes show that Dr Horley attended meetings on 24 October 1977,⁸⁴ 13 November 1978,⁸⁵ 20 and 21 November 1979⁸⁶ and 30 September 1980. He sent apologies for the meeting on 9 October 1981.⁸⁷ After beginning his term as Director in December 1983, Dr Kenny attended most meetings, only missing three annual meetings between 1983 and 1991.⁸⁸

51. Dr Horley was listed as a member of the British Society for Haematology for the Brighton Centre from 1978/1979,⁸⁹ and was still listed as a member in 1983/1984.⁹⁰ He had been a member for another hospital since at least 1967/1968.

52. Dr Kenny was informed in June 1983 of investigations conducted by the Treloar Haemophilia Centre into stigmata of AIDS on one of their shared patients.⁹¹ The patient did not clinically exhibit any stigmata of AIDS, and several “*AIDS related tests*” were conducted and were to be repeated due to the appearance of lymph nodes.

Testing for HIV/HCV and numbers of patients infected

53. Provisional UKHCDO data available to the Inquiry suggests that 6 people were infected with HIV at the Brighton Centre, all recorded as testing positive in 1985.⁹²

⁸³ DHSC0041402_008

⁸⁴ PRSE0001002

⁸⁵ HSOC0010549

⁸⁶ PRSE0003946

⁸⁷ CBLA0001464

⁸⁸ Meetings attended by Dr Kenny up to 1991: 21 October 1985 PRSE0001638, 17 March 1986 PRSE0001688, 9 October 1986 PRSE0004317, 29 September 1988 BART0002329, 9 October 1989 HCDO0000015_035, 21 September 1990 BART0002382, 7 October 1991 HCDO0000491_001

⁸⁹ BSHA0000122; BSHA0000114

⁹⁰ BSHA0000118

⁹¹ TREL0000041_003

⁹² INQY0000250

54. The Inquiry has received a number of accounts from infected individuals and affected families of how testing for HIV and HCV was arranged, and how results were communicated to them.
55. An Inquiry witness recalls that her late husband was asked to attend for regular blood tests in 1985 and was not told what the tests were for. Six weeks later, he attended to receive the results and was told that he was HTLV-III positive. The witness was tested immediately after as well, and stated that when she went to receive the results, *“We were not even sitting down in the doctor’s room. We were just told - whilst standing up - I was negative, he was positive.”*⁹³
56. Another Inquiry witness states that her late husband was told of his HIV test results over the phone in the mid-1980s; *“We just looked at each other and were in complete shock. I think it’s absolutely terrible that they delivered the news to him over the phone.”* Her husband had not known that he was being tested for HIV.⁹⁴
57. One Inquiry witness, upon reviewing her medical records, discovered she was screened for HTLV-III in 1986.⁹⁵ Further, in 1990, there was a record that she was HIV antibody negative. The witness did not know about this testing until she reviewed her records after the Inquiry began. The witness’ medical records from 1986 and earlier were labelled *“hepatitis risk,”* however, the witness was not diagnosed with hepatitis C until 2017 when she underwent routine testing prior to planned dental work.⁹⁶
58. An Inquiry witness recalls that her late husband was asked to attend an appointment to have blood taken for testing for both HIV and HCV in 1995. The witness recalls that her husband received his results via letter, which stated he was negative for HIV but positive for HCV.⁹⁷

⁹³ WITN0467001, §8-10

⁹⁴ WITN1710001, §6-7,14

⁹⁵ WITN1514001, §18-19; WITN1514005; WITN1514006

⁹⁶ WITN1514001, §12

⁹⁷ WITN0868001, §15-20; WITN0868003

Treatment of patients for HIV, or HCV, HBV

59. Dr Kenny attended a meeting of the South Thames Regional Haemostasis and Thrombosis Sub-Committee on 26 November 1996, which stated that some hospitals were experiencing financial problems purchasing Interferon therapy for their patients.

⁹⁸

60. An Inquiry witness recalls how her husband was not offered any treatment for hepatitis C after his diagnosis in the mid-1990s as there were no treatments available to him at the time. He was to have a liver transplant as treatment, however, due to having cancer, he never received the liver transplant.⁹⁹

61. The witness also recalls how in the months leading to her husband's death in 2004, they were able to keep some clotting factor at home, in a special fridge. Dr Kenny prepared a bespoke information leaflet about what to do and how to prepare the Factor IX concentrate, as well as including instructions to emergency services or hospitals for the witness and her husband.¹⁰⁰

Other information

62. In April 1984, Dr Kenny wrote to Dr Rizza regarding a clinical trial of Armour's "hepatitis reduced" Factor VIII products.¹⁰¹ The Centre had been approached by Armour about the possibility of entering patients into the trial. It is unclear if Dr Kenny did enter patients in the trial, however, by September 1984 the trial had been suspended after two patients in the trial contracted non-A, non-B hepatitis.¹⁰²

⁹⁸ HCDO0000277_174

⁹⁹ WITN0868001, §32, 58-59

¹⁰⁰ WITN0868001, §22-24; WITN0868004

¹⁰¹ OXUH0001891_003

¹⁰² HCDO0000561

EASTBOURNE DISTRICT GENERAL HOSPITAL, EASTBOURNE

The Centre

63. The Haemophilia Centre at the Eastbourne District General Hospital (“the Eastbourne Centre”) was designated as centre number 119.¹⁰³ The Hospital opened to patients in 1976.¹⁰⁴ The Director from the 1970s through to the 1990s was Dr Pamela Gover.¹⁰⁵
64. The Eastbourne Centre was part of the St Thomas’ Hospital Supraregion,¹⁰⁶ and designated as an Associate Centre within the South East Thames Regional Health Authority.¹⁰⁷ Prior to Eastbourne District General Hospital opening in 1976, St Mary’s Hospital was the other main hospital in Eastbourne. In 1973, St Mary’s was supplied with blood products from the South London Transfusion Centre, though it was not considered a Haemophilia Centre.¹⁰⁸

Numbers of patients treated

65. The available annual returns to 1985 record the following patient numbers:
- a. 1976: the Eastbourne Centre treated 4 haemophilia A patients.¹⁰⁹
 - b. 1977: the Eastbourne Centre treated 6 haemophilia A and 2 haemophilia B patients.¹¹⁰
 - c. 1978: the Eastbourne Centre treated 4 haemophilia A and 2 haemophilia B patients.¹¹¹
 - d. 1979: the Eastbourne Centre treated 3 haemophilia A and 2 haemophilia B patients.¹¹²

¹⁰³ HCDO0000119_138; DHSC0043425_064

¹⁰⁴ <https://www.esht.nhs.uk/history/the-nhs-at-70-years-old/nhs-70th-eastbourne-district-general-hospital/>

¹⁰⁵ HCDO0000138_007; BSHA0000114

¹⁰⁶ CBLA0000699

¹⁰⁷ DHSC0002347_015, p. 23; HCDO0001074

¹⁰⁸ DHSC0100026_178

¹⁰⁹ HCDO0001074

¹¹⁰ HCDO0001155

¹¹¹ HCDO0001254

¹¹² HCDO0001321

- e. 1980: the Eastbourne Centre treated 7 haemophilia A and 2 haemophilia B patients.¹¹³
- f. 1981: the Eastbourne Centre treated 7 haemophilia A and 3 haemophilia B patients.¹¹⁴
- g. 1982: the Eastbourne Centre treated 3 haemophilia A, 2 haemophilia B and 2 Von Willebrand's disease patients.¹¹⁵
- h. 1983: the Eastbourne Centre treated 3 haemophilia A, 3 haemophilia B and 1 Von Willebrand's disease patient.¹¹⁶
- i. 1984: the Eastbourne Centre treated 2 haemophilia A, 2 haemophilia B and 1 Von Willebrand's disease patient.¹¹⁷
- j. 1985: the Eastbourne Centre treated 5 haemophilia A, 2 haemophilia B and 1 Von Willebrand's disease patients.¹¹⁸

66. Throughout the period 1976 to 1985, the Eastbourne Centre's patients included children.

Blood product usage

- 67. In 1976, the Eastbourne Centre treated its haemophilia A patients with exclusively cryoprecipitate (6,230 units).¹¹⁹
- 68. In 1977, the Eastbourne Centre treated its haemophilia A patients with cryoprecipitate (11,000 units) and NHS concentrates (9,000 units).¹²⁰

¹¹³ HCDO0001418

¹¹⁴ HCDO0001516

¹¹⁵ HCDO0001617

¹¹⁶ HCDO0001714

¹¹⁷ HCDO0001809

¹¹⁸ HCDO0001901

¹¹⁹ HCDO0001074

¹²⁰ HCDO0001155

69. In 1978, the Eastbourne Centre treated its haemophilia A patients with cryoprecipitate (115,980 units), NHS concentrates (7,640 units) and commercial concentrates (Kryobulin) (4,000 units).¹²¹
70. In 1979, the Eastbourne Centre treated its haemophilia A patients exclusively with cryoprecipitate (8,890 units).¹²²
71. In 1980, the Eastbourne Centre treated its haemophilia A patients with commercial concentrates (8,158 units), cryoprecipitate (4,340 units) and NHS concentrates (2,020 units).¹²³
72. In 1981, the Eastbourne Centre treated its patients as follows:¹²⁴
- a. Haemophilia A patients were treated with cryoprecipitate (12,530 units), NHS concentrates (9,150 units) and commercial concentrates (Hemofil and Kryobulin) (7,920 units).
 - b. The patient with Factor VIII inhibitors was treated with cryoprecipitate, commercial concentrates (Factorate) and Autoplex.
73. In 1982, the Eastbourne Centre treated its patients as follows:¹²⁵
- a. Haemophilia A patients were treated with commercial concentrates (Factorate) (11,592 units) and NHS concentrates (6,975 units).
 - b. The patients with Von Willebrand's disease were treated with cryoprecipitate and commercial concentrates (Factorate).
74. In 1983, the Eastbourne Centre treated its patients as follows:¹²⁶
- a. Haemophilia A patients were treated with NHS concentrates (15,950 units) and commercial concentrates (Factorate) (1,650 units).

¹²¹ HCDO0001254

¹²² HCDO0001321

¹²³ HCDO0001418

¹²⁴ HCDO0001516

¹²⁵ HCDO0001617

¹²⁶ HCDO0001714

- b. The patient with Von Willebrand's disease was treated exclusively with NHS concentrate.

75. In 1984, the Eastbourne Centre treated its patients as follows:¹²⁷

- a. Haemophilia A patients were treated with NHS concentrates (18,490 units) and cryoprecipitate (420 units).
- b. The patient with Von Willebrand's disease was treated exclusively with NHS concentrate.

76. In 1985, the Eastbourne Centre treated its patients as follows:¹²⁸

- a. Haemophilia A patients were treated with NHS concentrates (18,430 units) and cryoprecipitate (1190 units).
- b. The patient with Von Willebrand's disease was treated exclusively with NHS concentrate.¹²⁹

77. Throughout the period 1976-1985, the Eastbourne Centre treated its haemophilia B patients exclusively with NHS Factor IX concentrates.

78. In February 1985, Dr Gover ordered heat-treated Factor VIII from Dr Snape for use with one patient who was on home treatment.¹³⁰

Treatment policies

79. Dr Gover also attended the meeting of the Regional Haematology Speciality Sub-Committee referred to in paragraph 22 above.¹³¹

¹²⁷ HCDO0001809

¹²⁸ HCDO0001901

¹²⁹ The Centre's annual returns for 1986-1990 are at HCDO0000360, HCDO0002087, HCDO0002179, HCDO0002273 and HCDO0002363

¹³⁰ BPLL0010609

¹³¹ DHSC0041402_008

Knowledge of risk of hepatitis/AIDS and HTLV-III

80. UKHCDO minutes show that Dr Gover attended meetings of haemophilia centre directors on 17 March 1986¹³² and 1 October 1993.¹³³ She is recorded as having sent apologies for the following meetings during the 1970s and 1980s: 24 October 1977,¹³⁴ 13 November 1978,¹³⁵ 9 October 1986,¹³⁶ 9 October 1989,¹³⁷ 21 September 1990.¹³⁸ However, it may be reasonable to assume that Dr Gover, as Director of the Eastbourne Centre, was sent minutes of the meeting that she did not attend in person.

81. Dr Gover joined as a member of the British Society for Haematology for the Eastbourne Centre from 1978/1979,¹³⁹ and was also in the 1983/1984 list of members.

¹⁴⁰

Testing for HIV/HCV and numbers of patients infected

82. Provisional UKHCDO data available to the Inquiry suggests that 1 person was infected with HIV at the Eastbourne Centre.¹⁴¹

83. An Inquiry witness states that he was tested for hepatitis C in November 1993 when he presented to the Eastbourne Centre for treatment for his knee. He had only received concentrates once before, in February 1983. He was not specifically called to be tested but rather asked at the time whether he had been tested before.¹⁴² He tested positive.

Treatment of patients for HIV, or HCV, HBV

84. An Inquiry witness describes how her late brother approached Dr Gover after his HIV diagnosis. He was diagnosed at St Thomas'.

¹³² PRSE0001688

¹³³ HCDO0000493

¹³⁴ PRSE0001002

¹³⁵ HSOC0010549

¹³⁶ PRSE0004317

¹³⁷ HCDO0000015_035

¹³⁸ BART0002382

¹³⁹ BSHA0000122; BSHA0000114

¹⁴⁰ BSHA0000118

¹⁴¹ INQY0000250

¹⁴² WITN3110001, §4, 6-7

“[Her brother] began hearing things about HIV on the television and in the news. He decided to go and speak to Dr Gover about it; she had always said that he could ring her up if he ever had any problems.”¹⁴³

“It would seem from [her brother’s] interview with Sian Edwards, that Dr Gover did not provide any information in relation to his HIV infection. She did not offer any counselling and did not provide [her brother] with any brochures or information leaflets. He describes being in the same situation as he was before he went for the appointment, but comments that she confirmed the diagnosis in the best way that she could.”¹⁴⁴

85. The same witness said that her brother *“wasn’t happy with the treatment he received at Eastbourne General in the earlier years. He had to wait in long queues, was in and out like a yo-yo and rarely got answers to his questions.”¹⁴⁵*

86. Another witness states that after his diagnosis with hepatitis C in late 1993, it was recommended in early 1995 that he begin Interferon therapy. He declined the treatment initially after hearing how severe the side effects could be. He received two separate courses of treatment in the late 1990s, however, both were unsuccessful. The witness was offered treatment again in 2018 but he declined as his liver function was normal and his scans had shown no abnormalities.¹⁴⁶

¹⁴³ WITN0473001, §46-47

¹⁴⁴ WITN0473006, §2e

¹⁴⁵ WITN0473001, §69

¹⁴⁶ WITN3110001, §11-12, 16, 18, 25-28

ST RICHARD'S HOSPITAL, CHICHESTER

The Centre

87. The Haemophilia Centre at St Richard's Hospital, Chichester ("the Chichester Centre") was designated as centre number 126.¹⁴⁷ The Director from the 1970s until the 1990s was Dr Christopher Bateman,¹⁴⁸ and during the 1990s was Dr Phillip Bevan.¹⁴⁹ Dr Bateman has provided a written statement to the Inquiry dated 24 March 2021.¹⁵⁰

88. The Chichester Centre is occasionally referred to as the Royal West Sussex Hospital.¹⁵¹ This hospital closed in 1972 but may have distributed treatment to haemophiliacs prior to the establishment of the specific Haemophilia Centre.¹⁵²

89. The Chichester Centre was part of the St Thomas' Hospital Supraregion.¹⁵³ It was an Associate Centre in the South West Thames Health Regional Health Authority.¹⁵⁴ However, Dr Bateman states that he "*never considered Chichester to be a Haemophilia Centre - rather a local treatment facility,*" due to the small number of patients treated.¹⁵⁵

90. The Chichester Centre was serviced by the South London Transfusion Centre in Tooting,¹⁵⁶ including in 1973, before it became an Associate Centre.¹⁵⁷

Relationship with other Haemophilia Centres

91. Dr Bateman stated that he referred two patients to Treloars.¹⁵⁸ These patients were also seen at Great Ormond Street, and St Thomas' Hospital.¹⁵⁹

¹⁴⁷ HCDO0000119_138; DHSC0043425_064, p. 9

¹⁴⁸ WITN5355001, §2

¹⁴⁹ HCDO0000013_269

¹⁵⁰ WITN5355001

¹⁵¹ CBLA0000728

¹⁵² <https://discovery.nationalarchives.gov.uk/details/r/a042b99e-b503-466c-9186-594312b12f66>

¹⁵³ HCDO0000602

¹⁵⁴ CBLA0000728; DHSC0002347_015, p. 23

¹⁵⁵ WITN5355001, §5

¹⁵⁶ DHSC0004584_026

¹⁵⁷ DHSC0100026_178

¹⁵⁸ TREL0000120_045; WITN5355001, §51

¹⁵⁹ TREL0000119_141

92. A further witness to the Inquiry states he was also treated at both Treloars' and Chichester Hospital.¹⁶⁰

93. In September 1975, Dr Bateman wrote to P. J. Kirk at Treloars' regarding his proposed study of patients with haemophilia. Dr Bateman stated:¹⁶¹

"1. We will certainly find it easy to give ... cryoprecipitate only when he needs treatment.

2. The blood samples that you require. We will certainly collect clotted blood samples whenever he has treatment. Are you going to put the children on prophylactic iron therapy?

3. I would be pleased to notify you if ... should develop hepatitis."

94. In his statement, Dr Bateman said he had no recollection of this study and that the date was earlier than he remembered being in contact with Treloars.¹⁶² A treatment card dated 15 May 1976 indicates the named patient's involvement in the study.¹⁶³

Number of patients treated

95. The available annual returns to 1985 record the following patient numbers:

- a. 1977: the Chichester Centre treated 10 haemophilia A patients, and 1 haemophilia B patient.¹⁶⁴
- b. 1978: the Chichester Centre treated 12 haemophilia A patients, and 1 haemophilia B patient.¹⁶⁵
- c. 1979: the Chichester Centre treated 12 haemophilia A patients.¹⁶⁶
- d. 1980: the Chichester Centre treated 10 haemophilia A patients.¹⁶⁷

¹⁶⁰ WITN3224001, §6

¹⁶¹ TREL0000250_016

¹⁶² WITN5355001, §52

¹⁶³ TREL0000064_017

¹⁶⁴ HCDO0001150

¹⁶⁵ HCDO0001247

¹⁶⁶ HCDO0001316

¹⁶⁷ HCDO0001412

- e. 1981: the Chichester Centre treated 11 haemophilia A patients.¹⁶⁸
- f. 1982: the Chichester Centre treated 10 haemophilia A patients.¹⁶⁹
- g. 1983: the Chichester Centre treated 11 haemophilia A patients, and 2 Von Willebrand's Disease patients.¹⁷⁰
- h. 1984: the Chichester Centre treated 10 haemophilia A patients.¹⁷¹
- i. 1985: the Chichester Centre treated 8 haemophilia A patients and 1 patient with acquired haemophilia A.¹⁷²

96. Throughout the period 1977 to 1985, the Chichester Centre's patients included children.

Blood product usage

- 97. In 1977, the Chichester Centre treated its haemophilia A patients with cryoprecipitate (37,940 units), and commercial concentrates (Kryobulin) (2,880 units). NHS concentrates were used for two patients but were supplied by Oxford, so records were not kept at the Chichester Centre.¹⁷³
- 98. In 1978, the Chichester Centre treated its haemophilia A patients with NHS concentrates (49,000 units) and cryoprecipitate (20,020 units).¹⁷⁴
- 99. In 1979, the Chichester Centre treated its haemophilia A patients with NHS concentrates (58,310 units), cryoprecipitate (18,340 units) and commercial concentrates (Koate) (3,190 units).¹⁷⁵

¹⁶⁸ HCDO0001510

¹⁶⁹ HCDO0001612

¹⁷⁰ HCDO0001709

¹⁷¹ HCDO0001804

¹⁷² HCDO0001896

¹⁷³ HCDO0001150

¹⁷⁴ HCDO0001247

¹⁷⁵ HCDO0001316

100. In 1980, the Chichester Centre treated its haemophilia A patients with NHS concentrates (24,000 units), cryoprecipitate (16,170 units) and commercial concentrate (Koate) (1,440 units).¹⁷⁶
101. In 1981, the Chichester Centre treated its haemophilia A patients with NHS concentrates (32,750 units) and cryoprecipitate (11,340 units).¹⁷⁷
102. In 1982, the Chichester Centre treated its patients as follows:¹⁷⁸
- a. Haemophilia A patients were treated with NHS concentrates (45,240 units), commercial concentrates (Kryobulin) (25,500 units), and cryoprecipitate (5,670 units).
 - b. The patients with Factor VIII inhibitors were treated with NHS concentrates and commercial concentrates (Kryobulin).
103. In 1983, the Chichester Centre treated its patients as follows:¹⁷⁹
- a. Haemophilia A patients were treated with NHS concentrates (78,125 units), commercial concentrates (Kryobulin) (9,145 units), and cryoprecipitate (7,770 units).
 - b. Von Willebrand's Disease patients were treated with NHS concentrates and cryoprecipitate.
 - c. The patient with Factor VIII inhibitors was treated with NHS concentrate and commercial concentrates (Koate).
104. In 1984, the Chichester Centre treated its patients as follows:¹⁸⁰
- a. Haemophilia A patients were treated with NHS concentrates (28,394 units) and cryoprecipitate (3,430 units).
 - b. The patient with Factor VIII inhibitors was treated with NHS concentrates.

¹⁷⁶ HCDO0001412

¹⁷⁷ HCDO0001510

¹⁷⁸ HCDO0001612

¹⁷⁹ HCDO0001709

¹⁸⁰ HCDO0001804

105. In 1985, the Chichester Centre treated its patients as follows:¹⁸¹
- a. Haemophilia A patients were treated with NHS concentrates (278,500 units), commercial concentrates (Kryobulin) (48,500 units) and cryoprecipitate (8,260 units).
 - b. The patient with Factor VIII inhibitors was treated with NHs concentrates and cryoprecipitate.
 - c. The patient with acquired haemophilia A was treated with plasma and whole blood.¹⁸²
106. In the years 1977 and 1978 when the Chichester Centre treated haemophilia B patients, NHS Factor IX concentrates were used.
107. In February 1985, Dr Bateman requested heat treated factor VIII concentrate for 3 patients.¹⁸³ All 3 patients were scheduled to be screened for HTLV-III in the weeks following the letter.

Treatment policies

108. Please refer to paragraph 20 and 21 under Royal East Sussex Hospital, Hastings. Both the South East and South West Thames Health Regions were overseen by Professor G. I. C. Ingram of St Thomas' Hospital.¹⁸⁴
109. The Chichester Centre reported 2 patients already on home treatment as at September 1977. The Chichester Centre was assigned 12 vials per month initially¹⁸⁵ and this was revised to 10 in November 1977.¹⁸⁶

¹⁸¹ HCDO0001896

¹⁸² The annual returns for years 1986-1990 are at: HCDO0000296_002, HCDO0002082, HCDO0002174, HCDO0002268 and HCDO0002358.

¹⁸³ BPLL0010628

¹⁸⁴ CBLA0000503

¹⁸⁵ CBLA0000704

¹⁸⁶ CBLA0000728

110. In his statement, Dr Bateman states that *“our supplies were always constrained and patients got the most appropriate product we had available or could get hold of at very short notice.”*¹⁸⁷

111. A witness to the Inquiry recalls that Dr Bateman warned her and her husband against American Factor VIII.

“Dr Bateman warned us that the boys should not have American Factor VIII because it had come from “dodgy prisoners.” I cannot recall when he told us this but it must have been after [our youngest son] was born because I remember him saying “your boys” shouldn’t have American Factor VIII. He told us that he would send British heat-treated Factor VIII to Treloars for the boys to be treated with.

*I believe Dr Bateman saved our boys’ lives because he tried to keep the boys on cryoprecipitate until Factor VIII was available. He was aware there was a UK shortage of Factor VIII”*¹⁸⁸

112. In a letter to the Department of Health dated 12 November 1991, regarding the proposal to form a new National Blood Authority, Dr Bateman and Dr Bevan expressed their disagreement with the proposal due to the benefits they were experiencing by directly contracting with the Blood Transfusion Centre at Tooting. Dr Bateman stated;

*“Until two years ago, the Blood Transfusion Centre at Tooting provided at best a poor and occasionally a dangerously bad service to this hospital. The introduction of a whiff of commercial realism to their management arrangements and the improved relationship between them and us has led to a dramatic improvement in the service we get from them”*¹⁸⁹

113. The letter went on to state that if a national body was formed, they felt it was essential that direct contractual and financial relationships between Health Authorities

¹⁸⁷ WITN5355001, §10

¹⁸⁸ WITN1077001, §8, 10

¹⁸⁹ DHSC0004584_026

and Regional Transfusion Centres were maintained to ensure standards of service were retained.

Knowledge of risk of hepatitis/AIDS and HTLV-III

114. UKHCDO minutes show that Dr Bateman attended the meeting of haemophilia centre directors on 9 October 1981.¹⁹⁰ In his statement, Dr Bateman described himself as a “*totally inactive member*” in relation to the UKHCDO.¹⁹¹ Dr Bevan only attended one meeting, on 12 September 1997.¹⁹² However, it may be reasonable to assume that both Dr Bateman and Dr Bevan were sent minutes of meetings that they did not attend.

115. Dr Bateman was a member of the British Society of Haematology from 1975/1976.¹⁹³ He was also Chairman of the Chichester Health Authority Medical Advisory Committee.¹⁹⁴

116. A letter from Dr Bateman to Dr Bidwell, dated 9 December 1977, reported a patient that was experiencing jaundice, with Dr Bateman adding “*I thought that it was important that you should know which batch numbers of factor IX he has had, so that any necessary checks can be made.*”¹⁹⁵

117. In his statement, Dr Bateman states that knowledge of AIDS began in 1982, and that knowledge of blood product infectivity followed within a year.¹⁹⁶

118. In 1987, Dr Bateman wrote to Dr Keith Rogers at the National Blood Transfusion Service, regarding a woman who had tested positive for HIV as the source of the infection was unknown.¹⁹⁷ Dr Bateman stated that she had received cryoprecipitate in 1981, and factor VIII in 1983. The letter states; “*A month later she got Non-A Non-B hepatitis, which has gone on to chronic active hepatitis. She is on steroids for this.*” In response, the National Blood Transfusion Service stated they had no record of

¹⁹⁰ CBLA0001464

¹⁹¹ WITN5355001, §75

¹⁹² HCDO0000497

¹⁹³ BSHA0000138

¹⁹⁴ WSUS0000035

¹⁹⁵ BPLL0008065

¹⁹⁶ WITN5355001, §21

¹⁹⁷ BPLL0006025

infections or sero-conversions from the factor VIII batch but had opened an incident file.

Testing for HIV/HCV and numbers of patients infected

119. Provisional UKHCDO data available to the Inquiry suggests that 2 people were infected with HIV at the Chichester Centre.¹⁹⁸

120. A letter from Dr Bateman to the Chichester Health Authority dated 12 September 1988 states that in the 2.5 years previous, 548 HIV antibody tests were conducted, with 6 returning positive results. Dr Bateman states that he believes 4 of these to be his patients.¹⁹⁹ The letter is in response to a draft district policy on HIV. The policy states that in the event that a HIV antibody test is requested, the persons to be tested must be fully counselled by a recognised counsellor before the test is performed. Dr Bateman disagrees with this and states;

"I do not think the District can make a blanket policy like that. It is appropriate advice when one is dealing with a fit person who is concerned that they may have been exposed, but it is not at all appropriate for a patient referred for investigation because of lymphadenopathy, chronic diarrhoea, thrombocytopenia, etc. etc. In these circumstances, if the consultant concerned feels the illness may be due to HIV infection he or she should be responsible for any counselling and investigations, and diagnostic procedures should not be delayed while the patient is referred to a District counsellor."

Treatment of patients for HIV, or HCV, HBV

121. In his statement, Dr Bateman said: *"haematologists played no part in the clinical care of these patients [those infected with HIV/AIDS]"*²⁰⁰

122. Dr Bevan attended a meeting of the South Thames Regional Haemostasis and Thrombosis Sub-Committee in 1996, where treatment for hepatitis C was discussed. It was stated that some hospitals were experiencing financial problems in purchasing

¹⁹⁸ INQY0000250

¹⁹⁹ WSUS0000034

²⁰⁰ WITN5355001, §55

Interferon for its patients.²⁰¹ It is unclear whether the Chichester Centre was one of these.

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MARCH 2022

²⁰¹ HCDO0000277_174