

SMALLER HAEMOPHILIA CENTRES PRESENTATION
ST. JAMES' HOSPITAL, LEEDS

Directors

1. The Directors of the Haemophilia Centre at St. James' Hospital, Leeds, (the Centre) during the 1970s-1980s were Dr Swinburne and Dr McVerry.
 - a. Dr Swinburne was sole Director of the Centre from around early 1970 until late 1985 (she succeeded Dr Goldie who died in or around early 1970).
 - b. Dr McVerry became a joint Director of the Centre with Dr Swinburne in late 1985. He had joined St James' Hospital a few months earlier as a consultant haematologist. Dr McVerry later became the Haemophilia Centre's sole Director upon Dr Swinburne's retirement in 1992. He remained in the position until his retirement in July 2011.

Relationship with other Haemophilia Centres

2. The Haemophilia Centre at St James' Hospital was based at Becket Street, Leeds, LS9 7TF. The Centre had a relationship with other haemophilia centres, for example Harrogate Hospital (which later became subsumed with the development of the Centre at St. James' Hospital) [[WITN4742001](#)]. Dr McVerry consulted Dr Peter Jones at Newcastle and explains in his statement that these consultations would have influenced his selection of blood products [[WITN3502004](#)].
3. The Centre was involved in sending Hepatitis Surveys to the Oxford Haemophilia Centre [for example [HCDO0000255_046](#); [HCDO0000259_144](#); and [HCDO0000255_045](#)] and notifications of new cases of Haemophilia A and Haemophilia B [[HCDO0000235_010](#)].

Facilities and staffing in the 1970s and 1980s

4. Dr Swinburne recalls that the Centre had its own laboratory in which it prepared cryoprecipitate. She formed a small team with three other consultants who would be available to give injections to patients at any time. Dr Swinburne also recruited and trained the first lay venepuncture staff [WITN3447001].
5. When Dr McVerry joined the Centre, there was initially a nurse whose main role was injecting and supplying Factor VIII [WITN3502004]. The nurse was subsequently replaced with a general services nurse and a secretary who maintained medication records. The Centre did not have a specialist haemophilia registrar, however the Centre shared haematology registrars [WITN3502007].
6. It appears that Dr McVerry and Dr Swinburne shared clinics from 1985 until mid-1986 when they decided to split the clinics and share responsibilities. Dr McVerry looked after adult patients and Dr Swinburne took responsibility for children [WITN3502001; WITN3502007]. According to Dr McVerry, he did not treat children at any stage during his career [BAYP0000007_149; WITN3502004].
7. At some stage between 1985 and 1991, Dr McVerry took over the management of coagulotherapies, including haemophilia. Dr Swinburne then had no further clinical involvement but remained as a joint Director until her retirement in 1991 [WITN3447001].
8. The Haemophilia Centre relocated to an annex facility at the Hospital, developing a haematology out-patient department with 4 to 5 rooms outside the main hospital buildings [WITN3502007].
9. The Centre applied for several grants towards its facilities and staff:
 - a. In 1980 the Centre applied to the Council of the Haemophilia Society, for a grant of £3,500 which was “*required for computer equipment in respect of an investigation of possible auto-immune factors in haemophiliac arthropathy.*” This appears not to have been granted [HSOC0019918_026].

- b. The Centre received a grant of £350 for equipment prior to 8 January 1981 [[HSOC0019919_023](#)] for a scanner to assist an investigation into chronic joint disease [[HSOC0019918_029](#)].
 - c. In 1981, the North East Group agreed that £2,000 should be granted to the Centre towards the salary of a part-time research assistant [[HSOC0019918_029](#)].
 - d. The Centre received a further grant of £1,000 in or around August 1982 [[HSOC0029476_014](#)].
 - e. In 1988, the Centre received funding which enabled it to recruit a senior haemophilia nurse, two part-time physiotherapists, social workers (including Sheila O'Rourke) and a data collection clerk [[WITN3502007](#)].
 - f. In 1990, Dr McVerry sought funding to provide a part-time physiotherapist for the Centre for 4 years. The Haemophilia Society Executive Committee approved a grant of £5,000 for one year only [[HSOC0010398](#)]. This appears to have been reconsidered and extended in 1991, with the Committee agreeing a further grant of £2,000 for a further year to enable a part-time physiotherapist to remain in post [[HSOC0019923_037](#)].
10. According to a 1990 bulletin, Sheila O'Rourke established a social work service at the Centre, namely a group support system for carers, patients, nurses and parents. The carer's group met for monthly sessions, which were used as an information sharing forum. Speakers were invited to attend and these sessions were combined with the support group formulated for patients. The patients' group met more frequently, namely every two weeks. Sheila O'Rourke also established a support group for nurses in the summer of 1989 to help improve the knowledge and skills of the nurses working directly with haemophilia and those affected by HIV. Other support groups included a group for parents of haemophiliac boys and a bereavement support group. [[HCDO0000279_011](#)].

Number of patients registered and treated

11. The available annual returns for the Centre to 1987 record the following patient numbers and treatment:

- a. 1978: the Centre treated 84 Haemophilia A patients (including 1 with Factor VIII antibodies), 10 patients with Haemophilia B and 4 with von Willebrand's disease. All patients registered with Haemophilia A and Haemophilia B, which included visitors, appear to have been treated. The annual return does not show the number of patients registered with von Willebrand's disease. The Centre treated both adults and children [[HCDO0001271](#)].
- b. 1981: the Centre treated 90 Haemophilia A patients (including 2 with Factor VIII antibodies), 9 Haemophilia B patients and 6 von Willebrand's disease patients in 1981. The number of patients registered appears to have been: 144 with Haemophilia A (including visitors), 20 with Haemophilia B and 16 with von Willebrand's disease. The Centre treated both adults and children [[HCDO0001536](#)].
- c. 1982: the Centre treated 98 Haemophilia A patients (2 with Factor VIII antibodies), 1 Haemophilia A carrier, 4 Haemophilia B patients and 8 von Willebrand's disease patients in 1982. This included both adults and children. The number of registered patients appears to have been: 154 with Haemophilia A (including visitors), 1 carrier of haemophilia A, 19 with Haemophilia B and 36 with von Willebrand's disease [[HCDO0001635](#)].
- d. 1983: the Centre treated 92 Haemophilia A patients (4 with Factor VIII antibodies), 1 carrier of haemophilia A, 11 patients with haemophilia B and 8 patients with von Willebrand's disease in 1983. The number of registered patients appears to have been: approximately 180 with Haemophilia A or Haemophilia B (including visitors),¹ 1 carrier of haemophilia A and 37 with

¹ Much of this annual return is only faintly legible and it is difficult to distinguish which pages relate to patients with Haemophilia A and those with Haemophilia B. The total number of patients has therefore been combined.

von Willebrand's disease. The Centre treated both adults and children [[HCDO0001734](#)].

- e. 1985: the annual return shows that 83 Haemophilia A patients (3 with Factor VIII antibodies), 8 Haemophilia B patients and 9 von Willebrand's disease patients were treated in 1985. The number of registered patients appears to have been: 176 with Haemophilia A (including visitors), 2 Haemophilia A carriers, 23 with Haemophilia B and 49 with von Willebrand's disease. The Centre treated both adults and children [[HCDO0001920](#)].
- f. 1986: the Centre treated 83 Haemophilia A patients (1 with Factor VIII antibodies), 1 Haemophilia A carrier, 6 patients with Haemophilia B and 9 von Willebrand's disease patients in 1986. This included both adults and children. The number of patients registered with the Centre appears to have been: 181 Haemophilia A patients, 2 Haemophilia A carriers, 23 Haemophilia B patients and 56 patients with von Willebrand's disease [[HCDO0002017](#)].
- g. 1987: the Centre treated 76 patients with Haemophilia A (1 with Factor VIII antibodies), 1 patient with Acquired Haemophilia A, 4 patients with Haemophilia B and 7 von Willebrand's disease patients in 1987. This included both adults and children. The number of patients registered with the Centre appears to have been: 184 patients with Haemophilia A (including visitors), 2 Haemophilia A carriers, 23 patients with Haemophilia B and 59 von Willebrand's disease patients [[HCDO0002105](#)].

12. In some instances, the Centre incorporated other hospitals' annual returns into its own. For example, a cover letter enclosing the 1976 annual return for the Harrogate General Hospital Associate Centre, signed by Dr McEvoy, refers to the details being sent to Dr Swinburne for incorporation into the Centre's annual returns for that year. The Harrogate General Hospital return shows that 9 haemophiliac patients and 1 patient with von Willebrand's were treated. All patients there were treated with cryoprecipitate [[HCDO0001082](#)].

Treatment policies and blood product usage

13. In a letter to the Department of Health and Social Security dated 11 March 1975, Dr Tovey (Director of the Regional Transfusion Centre in Leeds) wrote that the Leeds Haemophilia Centre was the largest user of cryoprecipitate in the area and had been insistent for years on making its own cryoprecipitate from fresh frozen plasma supplied to it by the Regional Transfusion Centre. The letter informs that 5,955 fresh frozen plasma donations were issued to the Centre in 1974 [[DHSC0002359_046](#)].
14. On 28 September 1974, Dr Swinburne attended the Leeds Group Annual General Meeting as a guest speaker. The film “Home Infusion” was shown and she took questions arising from it. A Haemophilia Society News Bulletin informs that Dr Swinburne “*was able to tell members of the present position regarding home treatment*” [[HSOC0022698](#)]. An Inquiry witness recalls commencing home treatment in or around 1974 [[WITN1291001](#)].
15. By 18 May 1977, the Centre had become aware of clinical jaundice occurring in 6 haemophilia patients treated with Factorate. All patients had also been treated with cryoprecipitate and it is possible that some had also been treated with other freeze-dried concentrates [[ARMO0000013](#)].
16. St James’ Hospital purchased Koate during 1977 [[IPSN0000536](#)].
17. In 1978, the Centre treated its patients as follows [[HCDO0001271](#)]:
 - a. Haemophilia A patients were treated primarily with commercial product (862,053 units of Factorate and 115,981 units of Kryobulin), though the Centre also used NHS factor VIII (590,335 units) and cryoprecipitate (5,000 units). 33 Haemophilia A patients were on regular home treatment. The Centre did not use cryoprecipitate to treat those with Factor VIII antibodies.
 - b. The Centre’s Haemophilia B patients were treated exclusively with NHS factor IX (99,935 units).

- c. Von Willebrand's disease patients were treated primarily with cryoprecipitate (5,000 units), however the Centre also treated them with NHS factor VIII (3,500 units), Armour factor VIII (2,000 units) and a small amount of Immuno factor VIII (810 units).

18. In August 1979, Speywood sent Dr Swinburne samples of Porcine Factor VIII and it was suggested that these be checked in the laboratory against the Centre's most difficult inhibitor cases [[IPSN0000324_013](#)].

19. In August 1980, the Centre received 49 vials of Factorate. The cover letter from Armour informs that the relevant batch had not yet been released by the DHSS, however it was nevertheless agreed that the Factorate could be provided because it was urgently required to meet patient need [[MHRA0000083_011](#)].

20. In a letter to Dr Aronstam dated 16 September 1980, Dr Swinburne wrote that she worked on "*variable doses according to the severity and site of the bleed*". Notably, in the same letter Dr Swinburne requested further details from Dr Aronstam before giving her support to a "*project*" in relation to one of her patients. Dr Swinburne suggests that she would not like this project to interfere with necessary treatment for her patient [[WITN1592015](#)].

21. In 1981, the Centre treated its patients as follows [[HCDO0001536](#)]:

- a. Haemophilia A patients with Factorate (162,197 units at hospital and 1,630,256 units for home treatment) and NHS Factor VIII (592,070 units at hospital and 52,750 units for home treatment). Those with Factor VIII antibodies were treated with 2,916 units of high potency Factorate, 2,700 units of Hyate C and 6,000 units of FEIBA.
- b. Haemophilia B patients were treated exclusively with NHS Factor IX concentrate (79,820 units at hospital and 13,985 units for home treatment).
- c. Von Willebrand's patients were treated with NHS Factor VIII (1,050 units) and cryoprecipitate (1,010 bags).

22. In 1982, the Centre treated its patients as follows [[HCDO0001635](#)]:

- a. Haemophilia A patients continued to be treated primarily with Factorate, with 2,292,790 units being used for home treatment and 64,485 units at hospital. The Centre also treated patients at hospital with NHS Factor VIII (404,955 units), and Bovine/Porcine Factor VIII (900 units). Patients with Factor VIII antibodies were treated with Factorate and Porcine Factor VIII only.
- b. The Centre treated carriers of Haemophilia A with NHS Factor VIII (1,175 units) and Factorate (2,060 units).
- c. Haemophilia B patients were treated using NHS Factor IX (40,440 units at hospital and 21,210 units for home treatment).
- d. The Centre's von Willebrand's disease patients were treated with Cryoprecipitate (654 bags), NHS Factor VIII (56,205 units at hospital and 56,875 units for home treatment) and Factorate (5,460 units at hospital and 18,170 units for home treatment).

23. In 1983, blood product usage at the Centre was as follows [[HCDO0001734](#)]:

- a. The Centre continued to treat its Haemophilia A patients primarily with Factorate (23,285 units at hospital and 1,642,244 units for home treatment). The Centre used an increased quantity of NHS Factor VIII from the previous year (571,980 units at hospital and 877,980 units for home treatment). Haemophilia A patients were also treated with Hemofil (21,160 units), Bovine/Porcine Factor VIII (13,800 units) and FEIBA (20,000 units). The Centre did not treat patients with Factor VIII antibodies with Hemofil or Bovine Factor VIII.
- b. The Centre's carrier of Haemophilia A was treated with NHS Factor VIII (1,805 units).
- c. Haemophilia B patients were treated exclusively with NHS Factor IX concentrate (4,000 units at hospital and 157,685 units for home treatment).

- d. To treat its von Willebrand's disease patients, the Centre used plasma (4 bags), cryoprecipitate (289 bags / 20,230 units), NHS Factor VIII (45,950 units at hospital and 31,330 units for home treatment) and Factorate (4,850 units).

24. In 1985, the hospital treated its patients as set out below [HCDO0001920]:

- a. Haemophilia A patients were treated with cryoprecipitate (21),² NHS Factor VIII (336,466 units at hospital and 717,010 units for home treatment), Profilate (84,086³ units for hospital patients and 514,026 units for home treatment), Factorate (385,015 units at hospital and 1,699,265 units for home treatment), Porcine Factor VIII (40,050 units) and FEIBA (249,000 units). Those patients with Factor VIII antibodies appear not to have been treated with cryoprecipitate or Profilate, however the Centre additionally treated them with NHS Factor IX.
- b. To treat its Haemophilia B patients, the Centre used NHS Factor IX (25,910 units at hospital and 2,185 units for home treatment) and commercial Factor IX, Profilnine (2,165 units at hospital and 74,360 units for home treatment).
- c. The Centre used cryoprecipitate (141),⁴ NHS Factor VIII (24,250 units for hospital patients) and Factorate (14,555 units at hospital and 9,900 units for home treatment) to treat its von Willebrand's disease patients.

25. In 1986, the Centre treated its patients as follows [HCDO0002017]:

- a. For Haemophilia A patients, the Centre used cryoprecipitate (179 bags / 12,530 units), NHS Factor VIII (in excess of 156,000⁵ units at hospital and 973,340 units for home treatment), Profilate (26,220 units for hospital patients and 72,100⁶ units for home treatment), Factorate (332,310⁷ units for hospital

² Measurement not specified.

³ Note this number is faint but it is understood to read as stated.

⁴ Unit not specified.

⁵ Note this number is faint but it is understood to read as stated.

⁶ Note this number is faint but it is understood to read as stated.

⁷ Note this number is faint but it is understood to read as stated.

patients and 1,322,055 units for home treatment) and Koate (142,500⁸ units for hospital patients and 766,880⁹ units for home treatment). In addition, the annual return shows that the Centre also used DDAVP, which appears to have been the first time (or at least the first time that it was recorded in the returns that are available to the Inquiry). Haemophilia A patients with Factor VIII antibodies were treated with NHS Factor VIII and commercial product (Factorate, Koate and Profilate).

- b. The Centre used DDAVP exclusively to treat its Haemophilia A carriers.
- c. In relation to its von Willebrand's disease patients, the Centre treated them with DDAVP, cryoprecipitate (228 bags / 15,760 units¹⁰), NHS Factor VIII (17,070 units at hospital and 2,500 units for home treatment), Factorate (51,555 units for hospital patients and 18,550 units for home treatment)¹¹ and Koate (8,080¹² units).
- d. Haemophilia B patients were treated with NHS Factor IX concentrate (6,210 units at hospital and 64,890 units for home treatment) and Profilate (4,590 units for hospital patients and 16,320 units for home treatment).

26. In 1987, the Centre treated its patients with the following [HCDO0002105]:

- a. Haemophilia A patients were treated with cryoprecipitate (79 bags / 5,530¹³ units), NHS Factor VIII (165,695 units at hospital and 625,700 units for home treatment), Profilate (121,630 units at hospital and 659,120 units for home treatment), Koate (340,320 units at hospital and 2,393,680 units for home treatment), Porcine Factor VIII (58,515 units), DDAVP and FEIBA (109,000 units). Those with Factor VIII antibodies were not treated with cryoprecipitate DDAVP or FEIBA.

⁸ Note this number is faint but it is understood to read as stated.

⁹ Note this number is faint but it is understood to read as stated.

¹⁰ Note this number is faint but it is understood to read as stated.

¹¹ Note the Factorate numbers are faint but it is understood to read as stated.

¹² Note this number is faint but it is understood to read as stated.

¹³ Note this number is faint but it is understood to read as stated.

- b. The Centre's Acquired Haemophilia A patient was treated with Porcine Factor VIII (38,200 units) and FEIBA (109,000 units).
- c. To treat its Haemophilia B patients, the Centre used NHS Factor IX concentrate (10,745 units at hospital and 108,025 units for home treatment).
- d. The Centre used cryoprecipitate (323 bags / 22,610¹⁴ units), NHS Factor VIII (6,980 units), Profilate (9,440 units), Koate (27,030 units at hospital and 27,210 units for home treatment) and DDAVP to treat its von Willebrand's disease patients.

Other documents

- 27. The Centre seems to have implemented a form of prophylaxis treatment for some patients. In a letter dated 1990, Dr McVerry wrote that he had started a patient on a trial of prophylactic Factor VIII [WITN3193005].

Knowledge of risk of hepatitis/AIDS and response to risk

- 28. Dr Swinburne and Dr McVerry regularly attended UKHCDO meetings of haemophilia centre directors. Dr Swinburne has told the Inquiry that she also gained information from smaller local meetings, some of which she organised [WITN3447001]. Both Dr McVerry and Dr Swinburne can therefore be taken to have been aware of the information on hepatitis and AIDS risks discussed and shared during those meetings and to have received copies of minutes of the meetings. In particular:

- a. Dr Swinburne attended the directors' meeting on 5 April 1971 at which Dr Biggs' work on the incidence of jaundice was discussed and directors were asked to provide details of patients who developed jaundice [HCDO0001014]. She also attended the October 1972 meeting at which Dr Biggs provided an update on her work.

¹⁴ Note this number is faint but it is understood to read as stated.

- b. Dr Swinburne attended the directors' meeting on 1 November 1974 at which Dr Biggs presented the results for 1973 of the study of jaundice and Dr Craske reported on the hepatitis outbreak in Bournemouth amongst patients who had received commercial Factor VIII [HCDO0001017].
- c. Dr Swinburne attended the September 1975 meeting at which Dr Gibbs presented a paper on the progress of the study of jaundice and there was a discussion about hepatitis, the use of liver function tests and pool sizes [OXUH0003735].
- d. She attended the January 1977 directors' meeting at which Dr Craske reported on his study of hepatitis (both hepatitis B and what was described as non-B hepatitis) in haemophilic patients receiving Hemofil [PRSE0002268].
- e. Both Dr McVerry and Dr Swinburne attended the directors' meeting in November 1978, at which Dr Craske presented a report on behalf of the Hepatitis Working Party [HSOC0010549].
- f. It appears likely that both attended (Dr McVerry at that stage representing the Royal Liverpool Hospital) the directors' meeting on 30 September 1980, at which Dr Craske discussed the various liver biopsy studies being undertaken at the Royal Free and Sheffield and it was noted that first-time exposure to large pooled factor VIII concentrate resulted in many cases of hepatitis [PRSE0003946]. The Glasgow symposium on "Unresolved problems in Haemophilia" at which there was a detailed discussion on liver disease in haemophilia (and which the Inquiry has looked at in earlier hearings) took place following the directors' meeting.
- g. Both Dr Swinburne and Dr McVerry attended the October 1981 directors' meeting at which Dr Craske presented a pre-circulated report on hepatitis and there was a discussion about chronic hepatitis and liver disease [CBLA0001464].

- h. Both attended the September 1982 directors' meeting at which the issue of AIDS was raised and Dr Craske asked directors to let him know if they had any cases of the syndrome [CBLA0001619].
 - i. Both would have received the 22 March 1983 letter and enclosures from Dr Craske which provided an update on AIDS and explained the criteria for reporting cases [HCDO0000517_001, HCDO0000517_002, HCDO0000273_078].
 - j. Dr McVerry attended the October 1983 directors' meeting at which Dr Chisholm raised the issue of reverting to cryoprecipitate due to the concerns about AIDS and there was discussion of the two cases of AIDS in haemophiliacs, including the Bristol case. Dr Craske also presented a report from the Hepatitis Working Party [PRSE0004440].
 - k. Both Dr McVerry and Dr Swinburne attended the September 1984 directors' meeting at which Dr Craske presented a report on the current AIDS situation [PRSE0003659].
29. Dr Swinburne attended a Haemophilia Centre Directors AIDS Group meeting, representing Dr McVerry, on 4 February 1991. At that meeting, Dr Swinburne contributed that no inquests were being held in Leeds as there was no need to report AIDS deaths to the coroner [HCDO0000539].
30. Dr McVerry has told the Inquiry in his statement that he read the British Journal of Haematology, The Lancet, Blood and the New England Journal of Medicine, [WITN3502007]. He thought he would have read Professor Preston's 1978 Lancet article about chronic liver disease. He says, however, that in the late 70s/early 80s "*We did not know what caused [NANBH] or that it could be serious*".

Testing for HIV/HCV

HIV

31. St. James' Hospital appears to have begun testing patients for HIV in late 1984, with a document showing a positive test result on 29 November 1984 [[OXUH0002221](#)]. Dr McVerry outlined in his statement that he was involved in HIV testing and blood tests would be taken at his weekly blood clinics. He does not recall whether patients were advised that they were being tested for HIV, however patients were not specifically called in for testing [[WITN3502007](#)].
32. Dr McVerry wrote to a patient on 3 August 1988 requesting consent to his case notes to analyse collected data. The letter confirms that tests had been conducted at the Hospital "*during the past three years [...] with the help of Professor Cooper at Leeds University*" [[WITN1783003](#)]. As such, it appears that regular testing for HIV at the Centre may have been taking place from mid-1985. It is unclear from the letter whether patients were aware that they were being tested in this way.
33. The Inquiry has received evidence from witnesses that they were tested for HTLV III and were not informed that the tests had ever been conducted. For example, one witness has provided medical records suggesting that the same sample was tested on 3 separate occasions between 14 August 1986 and 20 October 1987 [[WITN1111006](#)]. In her evidence, she states she was not ever told that she had been tested for AIDS [[WITN1111001](#)].
34. An Inquiry witness recalls a meeting being held in the lecture theatre at St. James' Hospital in the summer of 1986, at which they were told that HIV may be fatal [[WITN1291001](#)].
35. In relation to test results, another Inquiry witness has given evidence that he was not informed of his HIV status until 3 years after his diagnosis [[WITN1592001](#)].
36. Dr Swinburne has told the Inquiry that she and Dr McVerry were as transparent as they could be with patients and they did not experiment on them [[WITN3447002](#)]. Dr McVerry suggests that his patients would have been informed of their diagnosis in person and his policy was to seek permission from the patient before informing their GP or otherwise sharing the results with other services or agencies [[WITN3502007](#)]. The parent of a patient of Dr Swinburne has described being informed of her son's HIV status at a routine check-up appointment [[WITN3260001](#)].

37. Provisional UKHCDO data available to the Inquiry suggests that 53 Leeds patients were infected: 6 tested positive in 1984; 42 in 1985; and 5 in 1986 [INQY0000250].

HCV

38. Dr McVerry could not be sure that the Centre had started routinely testing for HCV by 1990. He recalls verbal consent was obtained from patients in relation to HCV testing [WITN3502007]. Dr McVerry states that his policy was to seek permission from patients before informing their GP or otherwise sharing results with other services or agencies [WITN3502007].
39. The Inquiry has received evidence from people treated at the Centre which suggests that there was a delay in patients being informed of their infections [for example WITN3193001]. Another witness has told the Inquiry that he does not recall being informed of his diagnosis at all, despite a handwritten note in his medical records stating that he had been told. He says that, if HCV had been mentioned to him, then he had never been told about the seriousness of it [WITN1291001].
40. Witnesses have told the Inquiry that they were informed of infection at routine appointments. Others recall being notified of infection more informally; for example a witness describes a nurse telling him in around 1984 that he was “*probably infected already*”, however he did not formally receive a diagnosis until 1990 [WITN1562001].
41. Many witnesses describe a lack of information provided to them about HCV either before or at the time of diagnosis. For example, one witness describes learning about the possibility of her HCV infection from a Haemophilia Society bulletin. She subsequently went to the Centre to make enquiries and it was then that she was tested [WITN1111001]. Another witness has told the Inquiry that she had to look HCV up following her late husband’s diagnosis because it was never explained [WITN0598001].
42. Another witness was informed she had NANB in September 1982 following a referral to the Centre by her GP, however she was told there was no treatment or cure but the

HCV would work its way out of her body within about 10 weeks. She was pregnant at this time and was advised to rest until the virus had gone, and later not to share toothbrushes with anyone [[WITN1879001](#)].

43. According to Dr McVerry, the Centre worked closely with the Hospital's Liver and Infectious Disease Unit from 1985, seeking their input when required [[WITN3502004](#)]. For instance, liver biopsies would have been undertaken by a hepatologist [[WITN3502006](#)].

44. The Inquiry has received a letter dated 6 June 1995 which refers to literature produced by St. James' Hospital in relation to HCV [[DHSC0003595_024](#)].

Other issues

45. St. James' Hospital conducted an open study in relation to a Hyate C product licence application in around 1983 [[IPSN0000008](#)].

46. On 22 March 1988, St. James' Hospital received notification for the recall of Koate [[BAYP0000005_057](#)] and the material appears subsequently to have been replaced [[BAYP0000011_058](#)]. According to the evidence of Dr McVerry, in response to the risk patients would have been informed to return any product they had and the product would have been taken off the shelves. Dr McVerry does not recall whether patients were then tested or what patients were told [[WITN3502007](#)].

47. Data from the Centre was contributed to published studies, including: *Porcine Factor VIII Therapy in Patients with Congenital Haemophilia and Inhibitors: Efficacy, Patient Selection, and Side Effects* by C R M Hay et al [[IPSN0000152_002](#)], and *The Incidence of factor VIII inhibitors in the United Kingdom, 1990-93* by B T Colvin et al [[HCDO0000115_001](#)].

48. Dr McVerry provided advice or consultancy services to pharmaceutical companies in so far as he recalls attending an education day organised by Baxter for which he received remuneration of approximately £500 per day plus expenses [[WITN3502004](#)]. Further, it appears that Dr McVerry agreed in principle to providing suitable patients

for a study of a Cutter product due to begin on 28 October 1986 [BAYP0000009_008], however Dr McVerry does not recall actually becoming involved in such a trial. Dr McVerry also met with Peter Mooney of Cutter on 24 July 1986 [BAYP0000008_324].

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