

SMALLER HAEMOPHILIA CENTRES

NEWPORT HAEMOPHILIA CENTRE

The Centre and relationship with other Haemophilia Centres

1. The Haemophilia Centre at the Royal Gwent Hospital, Newport, was designated as centre number 152. Dr J. Howard Jones was the Centre's Director from at least 1977 until the late 1980s, when he was succeeded by Dr Elizabeth Moffat.¹ Dr Moffat has provided a statement to the Inquiry in which she explains that she became a consultant haematologist at the Royal Gwent Hospital in 1989.² Her evidence is that all bleeding disorder patients in South Gwent were transferred to the care of the Cardiff Comprehensive Care Centre before 1988 (i.e. prior to her arrival).
2. The Centre was part of the Cardiff Supraregion of haemophilia centres.³ It was supplied with cryoprecipitate by the Welsh Regional Transfusion Centre ("RTC") in Cardiff: see, for example, an August 1976 letter from Dr Bevan at the RTC to Dr Maycock,⁴ as well as a list of products issued by the RTC in 1984.⁵
3. The available documents suggest that links between patients in Gwent and the Cardiff Haemophilia Centre existed from at least the 1970s. For example, Professor Bloom completed a 1978 jaundice survey form regarding a patient who lived in GRO-C noting that the patient had been on home treatment for some years.⁶ Similarly, an Inquiry witness with haemophilia A, born in 1981, has described first being seen at the Royal Gwent as a baby before being transferred to Cardiff.⁷

¹ See the annual returns referred to below, as well as HCDO0000379_002, HCDO0001189; HCDO0002213, HCDO0002119 and HCDO0002213.

² WITN5508001

³ HCDO0000138_012

⁴ CBLA0000409. For evidence of blood products supplied by the Welsh BTS in the second half of the 1960s, see HSSG0010144, HSSG0010122, HSSG0010146 and HSSG0010260.

⁵ BPLL0000837_016; BPLL0000837_018. A May 1990 report contains further detail on the history of the Welsh Regional Blood Transfusion Service [NHBT0000489_019].

⁶ OXUH0000350

⁷ WITN2331001

4. An Inquiry statement is also available from Jennifer Jones, who worked in nursing at the Cardiff Centre in 1972-1977 and 1981-2003.⁸ Ms Jones' statement explains that Cardiff's "*patients often also went to other hospitals*", including Newport (para 28). She states that, other than Morriston Hospital in Newport, "*these hospitals didn't necessarily have specialised doctors or nurses. If patients presented there they would just be given whatever treatment was in the fridge. The treatment would be appropriate but it might have been commercial*". Ms Jones adds that, "*whenever possible, we encouraged patients to come and see us in Cardiff because we were a comprehensive care unit with more specialised staff and as such could give patients a better overall standard of care*" (para 30).
5. In December 1984, the acting chief administrative pharmaceutical officer at South Glamorgan Health Authority wrote a paper on the existing and likely future cost of purchasing Factor VIII concentrate (in particular as a result of heat treatment).⁹ The document illustrates some of the links between the Cardiff and Newport Centres:
 - a. At the time of the paper, Royal Gwent Hospital had incurred £2,000 for the purchase of commercial factor VIII (as against £80,000 for the Cardiff Centre and £10,000 for Morriston Hospital).
 - b. The number of patients treated regularly at the Cardiff Centre was 80. 15% of these patients were resident in the GRO-A district.

Numbers of patients registered and numbers of patients treated

6. The Centre's annual returns record the following patient numbers to 1985:
 - a. In 1977 the Centre treated 3 haemophilia A patients.¹⁰

⁸ WITN3621001

⁹ HSSG0010053_006 and HSSG0010053_007. For Professor Bloom's comments on the paper, see HSSG0010053_005.

¹⁰ HCDO0001189

- b. In 1978 the Centre treated 1 haemophilia A patient, 1 haemophilia B patient and 1 patient with von Willebrand's disease.¹¹
- c. In 1979 the Centre treated 3 haemophilia A patients.¹²
- d. In 1980 the Centre treated 3 haemophilia A patients.¹³
- e. In 1981 the Centre treated 3 patients with haemophilia A and 1 von Willebrand's patient.¹⁴
- f. In 1982 the Centre treated 4 patients with haemophilia A and 1 with haemophilia B.¹⁵
- g. In 1983 the Centre treated 3 patients with haemophilia A and 1 von Willebrand's patient.¹⁶
- h. In 1984 the Centre treated 4 patients with haemophilia A and 1 von Willebrand's patient.¹⁷
- i. In 1985 the Centre treated 1 haemophilia A patient and 1 von Willebrand's patient.¹⁸

Blood product usage

- 7. In 1977, the Centre treated its haemophilia A patients with cryoprecipitate (5,470 units).¹⁹

¹¹ HCDO0001286

¹² HCDO0001355

¹³ HCDO0001452

¹⁴ HCDO0001553

¹⁵ HCDO0001652

¹⁶ HCDO0001749

¹⁷ HCDO0001843

¹⁸ HCDO0001936

¹⁹ HCDO0001189

8. In 1978, the Centre treated its patients as follows:²⁰
- a. The haemophilia A patient was treated with commercial concentrate (Hemofil) (1,161 units).
 - b. The haemophilia B patient was treated with NHS concentrate.
 - c. The von Willebrand's patient was treated with cryoprecipitate.
9. In 1979, Newport treated its haemophilia A patients with commercial concentrate (Hemofil) (1,550 units) and NHS concentrate (900 units).²¹
10. In 1980, the Centre treated its haemophilia A patients with cryoprecipitate (9,825 units) and commercial concentrate (Hemofil) (3,833 units) in hospital.²²
11. In 1981, the Centre treated its patients as follows:²³
- a. Haemophilia A patients were treated with commercial concentrate (Hemofil) (27,187 units) and cryoprecipitate (12,675 units) in hospital.
 - b. A von Willebrand's patient was treated with cryoprecipitate in hospital.
12. In 1982, the Centre treated its patients as follows:²⁴
- a. Haemophilia A patients were treated with commercial concentrate (Hemofil and Kryobulin) (9,950 units) and cryoprecipitate (1,875 units) in hospital.
 - b. A haemophilia B patient was treated with NHS concentrate in hospital.
13. In 1983, the Centre treated its patients as follows:²⁵
- a. Haemophilia A patients were treated with commercial concentrate (Kryobulin) (6,814 units) in hospital.
 - b. A von Willebrand's patient was treated with DDAVP in hospital.

²⁰ HCDO0001286

²¹ HCDO0001355

²² HCDO0001452

²³ HCDO0001553

²⁴ HCDO0001652

²⁵ HCDO0001749

14. In 1984, the Centre treated its patients as follows:²⁶

- a. Haemophilia A patients were treated with commercial concentrate (Factorate and Kryobulin) (7,883 units), NHS concentrate (3,090 units) and DDAVP in hospital.
- b. A von Willebrand's patient was treated with DDAVP in hospital.

15. In 1985, the Centre treated its patients as follows:²⁷

- a. A haemophilia A patient was treated with DDAVP in hospital.
- b. A von Willebrand's patient was treated with cryoprecipitate in hospital.

Knowledge of risk of hepatitis and HTLV-III/AIDS

16. It appears that Dr Jones was a member of the Hepatitis Advisory Group. A Dr JH Jones is recorded as having attended the Group's meetings in January,²⁸ February,²⁹ March,³⁰ June,³¹ July,³² and October³³ 1971.

17. Dr Jones attended the 13 November 1978 UKHCDO meeting.³⁴ It may be reasonable to assume that, as Director of the Newport Centre, Dr Jones would have received copies of the reports circulated for, and the minutes of, UKHCDO meetings that he did not attend.

Testing for HIV/HCV and number of patients infected

²⁶ HCDO0001843

²⁷ HCDO0001936

²⁸ DHSC0000114

²⁹ DHSC0003839_055

³⁰ DHSC0002567_047

³¹ DHSC0103097_015

³² DHSC0003839_047

³³ DHSC0000124

³⁴ HSOC0010549

18. UKHCDO data available to the Inquiry suggests that in 1985 no patients were identified as having been infected with HIV.³⁵ The data does not include results for 1984 or later years.

19. In her statement, Dr Moffatt describes her understanding that a patient – a child with mild-moderate haemophilia A – was infected with HIV as a result of treatment with concentrate at the Newport Centre:³⁶

“To my knowledge one patient (who was registered at Cardiff CCC) was infected with HIV as a consequence of blood product treatment at the Royal Gwent Hospital in the early 1980’s. Any other patients from Gwent were registered and under the care of the Haemophilia Reference Centre in Cardiff. To my knowledge the patient at the Royal Gwent Hospital who received the concentrate infusion was a child with mild to moderate haemophilia A. The boy’s treatment at the Royal Gwent Hospital was in 1985 and preceded my employment there.”

Other information

20. Royal Gwent Hospital made reports of homologous serum jaundice following blood transfusion to the Welsh Blood Transfusion Service as early as 1955.³⁷ A report from January 1963 by Dr Jones is available.³⁸ A report also exists from January 1971.³⁹

21. While it is unclear whether they would have been sent to or read by Newport Centre clinicians, annual reports by the Welsh Blood Transfusion Service highlighted the risk posed by hepatitis from the mid-1960s. Having recorded the number of cases of post-transfusion virus or serum hepatitis, the report for 1965 recorded: *“It is probably a correct surmise that there were other cases which have not become known of simply because of failure of some hospitals to ensure that the routine follow-up system of*

³⁵ WITN3826020. The table also records a negative result in 1981; it is unclear if that is a typographical error or reflects a test on a stored sample.

³⁶ WITN5508001 para 33.1

³⁷ DHSC0100013_056

³⁸ DHSC0100016_031

³⁹ DHSC0100019_240

*transfused patients is routinely adhered to. The mortality rate of serum hepatitis is high and every possible step should be taken to ensure the detection of carrier donors of the causal virus of serum hepatitis, and this is only practicable if cases of serum hepatitis are notified to the B.T.S. In the past 11 years there have been 109 cases of serum hepatitis of which 12, or 11 per cent, were fatal.*⁴⁰ The 1968 report recorded that there had been 9 cases of post-transfusion hepatitis that year, as well as the previous year, of which 2 had proved fatal in 1967 and 1 in 1968.⁴¹

22. During August 1989 correspondence with the Macfarlane Trust, Dr Moffat explained that all HIV positive patients in the area would already be registered with the Cardiff centre and were under the care of Professor Bloom.⁴²

23. In 1996, a survey of chronic hepatitis C in patients under the care of 11 South Wales hospitals, including the Royal Gwent, was proposed.⁴³

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⁴⁰ HSSG0010144

⁴¹ HSSG0010122 and HSSG0010146

⁴² MACF0000175_045 and MACF0000175_046

⁴³ DHSC0004783_051