# SMALLER HAEMOPHILIA CENTRES PRESENTATION NORTH DEVON DISTRICT HOSPITAL, BARNSTAPLE

### The Centre

- The Barnstaple Haemophilia Centre (the Centre) was based at North Devon District Hospital (previously North Devon Infirmary). The Centre appears to have been designated in or around 1976 [OXUH0003752\_049]. It was assigned centre number 12 and was within the North Devon Regional Health Authority.
- 2. The Directors during the 1970s to 1990s were Dr Tierney and Dr Attock. It is understood that Dr Attock replaced Dr Tierney as Director in 1978 [HCDO0001134].

### Numbers of patients treated at the Centre

- 3. In the following years, the numbers of patients treated at the Centre were as follows:
  - a. <u>1977</u>: the Centre treated 4 haemophilia A patients (including 1 with Factor VIII antibodies) [HCDO0001134].
  - b. <u>1978</u>: the Centre treated 7 haemophilia A patients (including 1 with Factor VIII antibodies), 1 haemophilia B patient and 2 patients with von Willebrand's disease [HCDO0001227].
  - c. <u>1979</u>: the Centre treated 5 haemophilia A patients (including 1 with Factor VIII antibodies) and 1 patient with von Willebrand's disease [HCD00001297].
  - d. <u>1980</u>: the Centre treated 5 haemophilia A patients (including 1 with Factor VIII antibodies) and 1 von Willebrand's disease patient [<u>HCDO0001391</u>].
  - e. <u>1981</u>: the Centre treated 5 haemophilia A patients (including 1 with Factor VIII antibodies) [HCDO0001490].

- f. <u>1982</u>: the Centre treated 8 patients with haemophilia A (including 1 with Factor VIII antibodies) and 2 haemophilia B patients [HCDO0001593].
- g. <u>1983</u>: the Centre treated 7 patients with haemophilia A (including 1 with Factor VIII antibodies), 1 patient with haemophilia B and 1 von Willebrand's disease patient [<u>HCDO0001689</u>].
- h. <u>1984</u>: the Centre treated 9 patients with haemophilia A, 1 carrier of haemophilia A and 2 haemophilia B patients [<u>HCDO0001785</u>].
- i. <u>1985</u>: the Centre treated 6 haemophilia A patients and 1 patient with haemophilia B [HCDO0001877].
- 4. The Centre did not keep records in 1976 [HCDO0000057\_003].

### Treatment policies and blood product usage

- 5. The Annual Returns for the Centre show that the following products were used in the following years:
  - a. <u>1977</u>: the Centre treated its haemophilia A patients with cryoprecipitate and commercial concentrate (Kryobulin). The main product used was cryoprecipitate (5,800 units), followed by commercial concentrate (514 units). The Centre also used FEIBA for the treatment of its inhibitor patients. [HCD00001134].
  - b. <u>1978</u>: the Centre treated its haemophilia A patients with cryoprecipitate and commercial concentrate (Koate, Hemofil and Kryobulin). The main product used was commercial concentrate (19,648 units), followed by cryoprecipitate (8,591 units). The Centre also used FEIBA for the treatment of its inhibitor

patients. The Centre's haemophilia B patients were treated with plasma<sup>1</sup> and von Willebrand's disease patients with cryoprecipitate [HCDO0001227].

- c. <u>1979</u>: the Centre treated its haemophilia A patients with cryoprecipitate, NHS concentrate and commercial concentrate (Hemofil and Kryobulin). The main product used was commercial concentrate (68,090 units), then cryoprecipitate (6,125 units) and lastly NHS concentrate (470 units). The Centre also used FEIBA for the treatment of its inhibitor patients. The Centre treated the von Willebrand's disease patient with cryoprecipitate [HCDO0001297].
- d. <u>1980</u>: the Centre treated haemophilia A patients with cryoprecipitate and commercial concentrate (Hemofil and Kryobulin). The Centre primarily used commercial concentrate (21,045 units)<sup>2</sup>, followed by cryoprecipitate (715 units). The Centre also used FEIBA for the treatment of its inhibitor patients. The von Willebrand's disease patient was treated with cryoprecipitate [HCD00001391].
- e. <u>1981</u>: haemophilia A patients were treated with NHS concentrate and commercial concentrate (Kryobulin). The main product used was NHS concentrate (67,850 units). The Centre used 20,890 units of commercial concentrate [HCDO0001490].<sup>3</sup>
- f. <u>1982</u>: the Centre treated its haemophilia A patients with cryoprecipitate and NHS concentrate. The main product used was NHS concentrate (23,035 units)
  <sup>4</sup>, followed by cryoprecipitate (5,515 units). Haemophilia B patients were treated exclusively with NHS Factor IX concentrate [HCDO0001593].
- g. <u>1983</u>: the Centre treated its haemophilia A patients exclusively with NHS concentrate (60,670 units).<sup>5</sup> The von Willebrand's disease patient was treated

<sup>&</sup>lt;sup>1</sup> See annotation which reads "Plasma (for Christmas)".

<sup>&</sup>lt;sup>2</sup> The total amount of commercial concentrate includes the amount used for the treatment of inhibitor patients.

<sup>&</sup>lt;sup>3</sup> All figures for 1981 include the amount of product used for the treatment of inhibitor patients.

<sup>&</sup>lt;sup>4</sup> The total amount of NHS concentrate includes the amount used for the treatment of inhibitor patients.

<sup>&</sup>lt;sup>5</sup> The total amount of NHS concentrate includes the amount used for the treatment of inhibitor patients.

with cryoprecipitate and the Centre's haemophilia B patient with NHS Factor IX concentrate [HCD00001689].

- h. <u>1984</u>: the Centre treated its haemophilia A patients with plasma, NHS concentrate and commercial concentrate (Kryobulin). Haemophilia A patients were treated primarily with commercial concentrate (104,732 units), followed by NHS concentrate (39,775 units) and finally plasma (22)<sup>6</sup>. The carrier of haemophilia A was treated with NHS concentrate, and haemophilia B patients were treated with NHS Factor IX concentrate [HCD00001785].
- i. <u>1985</u>: the Centre treated haemophilia A patients with NHS concentrate and commercial concentrate (Kryobulin). Commercial concentrate was the main product used (154,621 units), followed by 30,890 units of NHS concentrate. Haemophilia B patients were treated with NHS Factor IX concentrate [HCD00001877].
- In March 1985, Dr Attock wrote to Dr Snape (BPL) identifying 4 patients who would benefit from heat treated material [BPLL0010577].

## Knowledge of risk of hepatitis / AIDS and response to risk

- 7. UKHCDO minutes suggest that Dr Tierney did not attend the UKHCDO meetings of haemophilia centre directors regularly or at all.
- UKCHDO minutes show that Dr Attock attended the UKHCDO meetings of haemophilia centre directors on the following dates: 17 October 1983 [PRSE0004440]; 27 September 1984 [PRSE0003659]; 21 September 1990 [BART0002382]; 7 October 1991 [HCDO0000491\_001]; 30 September 1994 [HCD00000494]; and 1 October 1998 [BART0000947].

<sup>&</sup>lt;sup>6</sup> The Annual Return does not specify the measurement for plasma.

9. It may be reasonable to assume that, as directors, Dr Attock and Dr Tierney would have received copies of the reports circulated for, and the minutes of, UKHCDO meetings for any meetings at which they were not in attendance.

#### Testing for HIV / hepatitis and numbers infected

- 10. Provisional UKHCDO data available to the Inquiry suggests that no patients were infected with HIV at the Centre [INQY0000250].
- 11. The Inquiry has received a written statement from a witness whose son was under the Centre's care during the 1970s to 1980s [WITN1428001]. From the early 1980s, his care was shared with Lord Mayor Treloar College (Treloar) after accepting a placement at the school. National Haemophilia Database records confirm he first tested positive for HIV on 11 October 1984 [WITN1428002]. He also contracted HCV but the witness does not know when her son was informed of this. The witness recalls being informed of her son's HIV status in November 1988 by Dr Attock, who sought her consent to inform her son and whom she recalls was then told in November 1988. The witness was not provided with any information regarding the risks associated with Factor VIII prior to her being told about her son's blood and to keep it to themselves [WITN1428001]. Correspondence between Dr Wassef (Treloar) and Dr Attock suggests:
  - a. in July 1983, Dr Wassef updated Dr Attock in relation to "AIDS Related Investigations", enclosing AIDS related tests which had been undertaken at Treloar and which Dr Wassef stated would be repeated before the end of term [TREL0000271\_132].
  - b. in April 1984, Dr Wassef confirmed "he is HBsAg negative, Anti HBc positive and Anti HBe positive" [TREL0000271\_127].

- c. in March 1985, Dr Wassef informed Dr Attock that he was first tested on January 1984, receiving an equivocal result which later became positive on a specimen taken on 11 October 1984 [<u>TREL0000271\_122</u>].
- d. on 18 December 1987, Dr Attock met with the witness and her son during which he "[...] explained his HIV status to both [GRO-B] and his mother and its distinction from AIDS and expected some questions but none where forthcoming. [GRO-B] is aware of the help which can be obtained from the Haemophilia Society if expenses are incurred [...]" [TREL0000271\_107].
- 12. The Inquiry does not currently have information as to the numbers of patients infected with hepatitis C in consequence of their treatment for haemophilia at North Devon District Hospital.
- 13. Post-transfusion hepatitis surveys were completed in respect of patients transfused at the North Devon Infirmary in December 1970 [DHSC0100019 125].

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