# SMALLER HAEMOPHILIA CENTRES PRESENTATION MAELOR HOSPITAL

#### Directors, relationship with RTC and staffing

- Maelor Hospital ("Maelor" or "the Centre") was a very small haemophilia centre, treating a handful of bleeding disorder patients in the 1970s and 1980s.
   In a 1990 list it was described as not an official centre and as being subject to special arrangements [HCDO0000119\_138], though it had a UKHCDO number (centre 070) from at least 1981 [HCDO0001546].
- 2. The identity of the Centre's director during the 1970s and 1980s is not always clear. Maelor's 1982 and 1983 returns, which appear to have been provided alongside those from Royal Manchester Children's Hospital ("RMCH"), listed Dr Geraint Owens as director [HCDO0001646 p.19 [HCDO0001744 p.17]. The Centre's 1985 return listed Dr Evans then director of RMCH as director [HCDO0001929].
- 3. Other staff in the 1970s include Dr Wise [DHSC0100026\_064], Dr Thompson [TREL0000225\_050], Dr Harris [TREL0000225\_046] and Dr Roberts [TREL0000225\_030]. Dr David Watson was a consultant haematologist at Maelor between at least the mid-1980s [CBLA0002183] and early 1990s [HSOC0022992].
- 4. Maelor had a relationship with Liverpool Regional Transfusion Centre: see, for example, a May 1973 document recording that Liverpool RTC supplied cryo to Maelor (as well as other hospitals in North Wales) [DHSC0100026\_064]. Liverpool RTC also supplied blood to Maelor: see, for example, records from 1983 [NHBT0084583], 1984 [NHBT0084578], 1985 [NHBT0084573] and 1987 [NHBT0084565]. Liverpool RTC continued to supply blood and blood products to Maelor in 1989-1990 [BCUH0000050]. A document written in 1994, in the context of a proposal to move the supply of blood to hospitals in

North Wales from Liverpool to Cardiff, provides further background on the links between Maelor and the Liverpool RTC [NHBT0009875 036].

#### Number of patients treated, product usage and treatment policies

Annual returns to 1986

- 5. The available annual returns for Maelor to 1986 record the following patient numbers and blood product usage:
  - a. 1981: one haemophilia B patient was registered and treated with NHS factor IX in hospital (4,385 units) [HCDO0001546].
  - b. 1982: one haemophilia A patient was treated with cryo in hospital (36 bags) and one haemophilia B patient received NHS factor IX, also in hospital [HCDO0001646 from p.19]. These appear to have been the only registered patients.
  - c. 1983: one haemophilia B patient was registered and treated with NHS factor IX in hospital (9,020 units) [HCDO0001744 from p.17]. A haemophilia A patient also appears to have been registered but not treated.
  - d. 1984: one haemophilia B patient was registered and treated with NHS factor IX in hospital (12,600 units) [HCDO0001836]. A haemophilia A patient again seems to have been registered but not treated.
  - e. 1985: one haemophilia B patient was registered and treated with NHS factor IX in hospital (8,500 units) [HCDO0001929]. A haemophilia A patient appears to have been registered but not treated.
  - f. 1986: one haemophilia B patient was registered and treated with NHS factor IX at home (13,350 units) [HCDO0000310\_009 and HCDO0000310\_008]. A haemophilia A patient seems again to have been registered but not treated.

- 6. While no annual returns from the 1970s are available, documents relating to two patients with haemophilia A, whose care was shared with Treloar's, provide some insight into Leighton's treatment policies.
- 7. Documents concerning the first patient are of particular interest in relation to the use of cryo versus concentrate, home treatment and the availability of NHS and commercial material.
  - a. A January 1974 letter from Dr Thompson of Maelor shows that the patient was treated with cryo at hospital during the Christmas holidays [TREL0000225 063].
  - b. In 1975 clinicians at Treloar's and Maelor corresponded about placing the patient on a home treatment programme with cryo. In October 1975, Dr Kirk of Treloar's explained that the patient had been taught to give himself cryo and, as he had a deep freeze at home, "wondered about the possibility of him being placed on a home treatment programme" [TREL0000225\_051]. Dr Thompson queried whether the deep freeze was sufficiently reliable but suggested that "the best thing would be to give this a try during the coming short winter holiday" [TREL0000225\_050]. Dr Kirk commented that Dr Thompson had made a "valid point concerning the suitability of a domestic freezer for the storage of cryoprecipitate"; if the freezer only went down to -20°C, he thought it "would be suitable for short-term storage, say, one month" [TREL0000225\_049].
  - c. In a May 1976 letter to Treloar's, Dr Harris of Maelor recorded that the patient who was then around 14 years old had attended a number of times during the Easter holiday and had been injecting himself with cryo [TREL0000225\_046].
  - d. In the summer of 1976 the patient was moved from cryo to concentrate. In a June 1976 letter, Dr Kirk explained that, as a result of a large cyst with a poor prognosis and frequent bleeding episodes, he had decided to

place the patient "on a prophylactic regime with Factor VIII concentrate" [TREL0000225\_044]. The clinicians had discussed the availability of cryo for home treatment but Dr Kirk was "a little reluctant to recommend this as we have recently seen one or two very serious reactions to Cryoprecipitate." In light of the difficulties some hospitals were having in purchasing concentrate, he suggested that Treloar's supply the product (Kryobulin), which would be provided directly by the manufacturer and could be collected by the patient or his family.

- e. A July 1976 letter records that Immuno subsequently sent the Kryobulin to Dr Thompson [TREL0000225\_039]. In September 1976 Dr Harris recorded that this material was distributed to the patient every two weeks during the summer holiday and that he had administered it to himself at home [TREL0000225\_038].
- f. In March 1977 Dr Kirk recorded that, as the patient had been progressing well for over a year, it had been decided to take him off his prophylactic regime and it was recommended that he go on home treatment therapy [TREL0000225\_034].
- g. In September 1977, Dr Painter of Treloar's noted that the patient was fully trained in home therapy and asked Dr Roberts of Maelor if he could be supplied with concentrate for use during the school holidays, possibly from Liverpool [TREL0000225\_033]. In December 1977, Dr Roberts explained that Liverpool Blood Transfusion Centre could only supply Lister concentrate, rather than Kryobulin, and raised concerns about the development of antibodies [TREL0000225\_030]. Dr Painter responded to confirm the patient would be trained with Lister concentrate and explained that there should be no greater risk of antibodies than with commercial material [TREL0000225\_029]. Dr Roberts subsequently confirmed that Maelor had obtained a supply of Lister material [TREL0000224\_039].
- h. Treloar's put the patient on another course of prophylactic treatment with concentrate in April 1978, following a bad bleed into the knee [TREL0000225\_024]. Dr Roberts noted that it could be difficult for Maelor to obtain sufficient supplies from Liverpool RTC for the

- treatment to continue during the summer holidays and explained that, in previous years, Maelor had been forced to use cryo when there were problems with obtaining factor VIII [TREL0000225\_022].
- i. The patient left Treloar's in 1979 [TREL0000225\_014]. His 1973-1979 treatment record shows that he mainly received cryo until the mid-1970s before concentrate became his primary treatment from 1976 [TREL0000225\_003]. This was initially with Kryobulin but from 1977 with a range of products (including Kryobulin, Hemofil, Koate, Factorate and Lister).

## 8. Documents concerning the second patient illustrate a number of similar themes:

- a. In a September 1972 letter to Treloar's, Dr Thompson of Maelor recorded that the patient, who was then around 11 years old, had been treated with cryo and EACA during a dental extraction [TREL0000311 050].
- b. The patient received cryo when treated at Maelor during the 1973-1974 Christmas holiday [TREL0000311\_048]. He was again treated with cryo when he attended Maelor during the 1976 Easter holiday [TREL0000311\_044].
- c. During 1977 there was a series of correspondence between Maelor, Treloar's and Liverpool Royal Infirmary about the patient's treatment during the upcoming summer holiday. It was proposed that, in light of the distance between his family home and Maelor, he be taught home therapy [TREL0000311 038] and [TREL0000311 037]. Cryo initially appears to have been proposed for this; however, a domestic freezer was thought not to be suitable long-term storage and the patient's GP did not have necessary storage facilities [TREL0000311 036, TREL0000311 035, TREL0000311 034, TREL0000311 033, TREL0000311 032 and TREL0000311 031]. The patient was therefore trained to treat himself with Lister concentrate [TREL0000311 030], which was obtained from Liverpool Royal [TREL0000311 028, TREL0000311 027, Infirmary TREL0000311 026, TREL0000311 025 and TREL0000311 024].

- d. The patient's 1972-1979 Treloar's treatment record shows that he was treated primarily with cryo until 1977, when concentrate became the main source (initially Lister, but also Hemofil, Kryobulin, Koate and Factorate) [TREL0000311\_006].
- 9. In June 1985, following a request from the Liverpool RTC director, Dr Watson provided the names of three Maelor patients for BPL heat-treated concentrate [CBLA0002183].
- 10. In 1986 Maelor was one of several centres involved in returning batches of Factorate [ARMO0000811].<sup>1</sup>

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

- 11. Correspondence between Maelor and Treloar's regarding the two patients described above includes some reference to hepatitis. For example, in a December 1974 letter, Treloar's informed Maelor that the second patient had received a batch of Hemofil which was almost certainly infected with hepatitis B [TREL0000311\_045]. Around September 1975, both patients were put forward for a proposed hepatitis study [TREL0000311\_042].
- 12. Little information is otherwise available on Maelor clinicians' knowledge of and response to hepatitis and AIDS. Dr Owens is not recorded as attending any UKHCDO meetings in the 1970s or 1980s. Dr Evans' understanding of hepatitis and AIDS is addressed in the note on RMCH.
- 13. The Inquiry has received a statement from the widow of a patient with hypogammaglobulinaemia (an immunodeficiency) who was infected with hepatitis C [WITN0102001]. The patient received monthly infusions of fresh frozen plasma from 1978 to 1987 at Maelor [WITN0102004 WITN0102005]. The patient's death was subject to an inquest; one of his causes of death was

<sup>&</sup>lt;sup>1</sup> This followed reports of seroconversion following the use of heat-treated material.

found to be hepatic cirrhosis due to chronic hepatitis C infection following multiple transfusions of fresh frozen plasma [WITN0102006].

### Other issues

14. A number of documents from the 1990s are available concerning patients' infection with hepatitis C following blood transfusions in the 1980s. These include a patient who received a transfusion in 1987 during a complicated pregnancy termination [NHBT0095473\_008 and NHBT0095473\_007], one who received transfusion support during renal surgery late in 1981 [NHBT0081182\_008, NHBT0081182\_007 and NHBT0081182\_006], and another who received a transfusion in 1985 [NHBT0095473\_089]. An update on the progress of the hepatitis C look back exercise at Maelor and other Welsh hospitals was provided in January 1996 [NHBT0036645].

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