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RESOURCES REQUIRED FOR ADEQUATE TREATMENT OF SCOTTISH HAEMOPHILIACS

Considerable thought is being given at the present time in the United Kingdom to the problem of haemophilia and in particular to the resources required to provide adequate treatment of patients suffering from the condition. This paper is an attempt to set down as a basis for discussion some facts provided by Haemophilia Directors and Regional Transfusion Directors relating to the position in Scotland.

Estimated number of haemophiliacs

The information obtained is summarised in Table 1. The numbers refer to registered haemophiliacs and are subject to a degree of inaccuracy in that patients for example may be registered at the Royal Infirmary Glasgow and receive their routine treatment at Dumfries Royal or Ballochmyle. The method of classifying the severity of the conditions is also open to criticism but the table does give a fairly accurate indication of the size of the problem, as far as it is known, in Scotland.

TABLE 1

	ABERDEEN	DUNDEE	EDINBURGH	GLASGOW	INVERNESS	TOTAL
No of registered haemophiliacs	25	17	95	285	14	436
(a) Hardly ever require specific therapy	11	7	6-9	((15	5	
(b) Require therapy not more than twice/year	6	1	9-12	(0	
(c) Require therapy 3 or 4 times/year	1	1	8-10	8	2	20-22
(d) Require more frequent therapy	7	8	25-30 ¹	40 ²	7	87-92

1. Within this category there is a core of about 12-15 patients who are each regularly transfused more than 10 times per year.

2. Most of these patients are treated between 20/60 times per year.

The remainder of the patients ie those not included in (a) (b) (c) or (d) in Table 1 (222 individuals) registered at the Royal Infirmary Glasgow Haemophilia Centre have not been seen there within the past year. A proportion of them

however receive treatment at the Royal Hospital for Sick Children, Yorkhill, or at other hospitals in the West of Scotland. Such information as is available suggests that some are treated as follows:-

- (i) 9 are treated at Dumfries and can be broken down accurately to the classification in Table 1 to (a) 6, (b) 1, (c) 1, (d) 1.
- (ii) 3 receive treatment at the Western Infirmary Glasgow.
- (iii) 5 receive treatment at Ballochmyle - classification (c) 4 (d) 1.
- (iv) Small quantities of cryoprecipitate are also issued to Falkirk Royal Infirmary and Law Hospital.

Factor VIII requirements

TABLE 2

Issue of Antihaemophilic Therapeutic Material by RTDs
during period January-June 1976

	ABERDEEN	DUNDEE	EDINBURGH	GLASSGOW	INVERNESS
As Cryoprecipitate	467	121 ¹	5965 ²	8829 ³	154
	donations	donor packs	donations	donations	donations
As PFC Factor VIII	288	111 ¹	307,700 ²	1381 ³	358
	vials	vials	units (1231 vials)	vials	vials
As Commercial Factor VIII (not issued by RTDs)	NIL	NIL	NIL	90740 units (Glasgor Royal)	NIL

1. There has been a gradual change over to PFC Factor VIII and no cryoprecipitate was used during the second 3 months.
2. These figures compare with 4,245 cryoprecipitate and 39,680 units PFC Factor VIII in Jan-June 1975. In Jan-June 1976 two patients between them consumed 200,000 units.
3. These figures compare with 26,616 cryoprecipitate and 1023 PFC Factor VIII for full year 1975.

Dr Davies has pointed out that in 1975 one patient had more than 60,000 units, three patients had between 40,000-60,000 each, five had between 30,000-40,000 units each, five had between 20,000-30,000 each, four had 15,000-20,000 each, six had between 10,000-15,000 each and five had between 5,000-10,000 each. The remainder used less than 5,000 each. These findings are in agreement with those reported in the paper "Cost of Management of Patients with Haemophilia" by Dr Prentice and colleagues in the Lancet of 21 August page 465 where it is stated that 20% of the haemophiliacs accounted for 80% of the resources used.

Home TherapyTABLE 3

Aberdeen	1(modified)	- PFC Factor VIII/Cryoprecipitate
Dundee	2	- PFC Factor VIII
Edinburgh	4	- PFC Factor VIII
Glasgow	3	- PFC Factor VIII
Inverness	1	- PFC Factor VIII

Possible Topics for Discussion

There are several factors which influence the total requirements for Factor VIII (whether as cryoprecipitate or intermediate concentrate); these include -

- (a) the number of moderate and severe haemophiliacs in the community
- (b) the amount of Factor VIII required by each patient
- (c) using the available resources in the most effective and efficient manner - eg by early treatment.
- (d) the advice given to patients as to the pattern of life (including work and recreation) they should follow; eg whether severe haemophiliacs are advised to live within the limitations imposed by their handicap as people with other severe disabilities have to do.
- (e) the effect of home therapy on total Factor VIII consumption;
- (f) the degree of co-operation and involvement in mutual decision making between the clinician who decides on patient's suitability for home therapy and the transfusion director who has to maintain a regular supply of intermediate concentrate, the supply of which is dependent on the amount of fresh plasma sent for fractionation.

- (g) the degree of follow-up and evaluation carried out into the care of haemophiliacs, particularly severe cases. As the number is not large this might warrant the setting up of a national register.
- (h) the introduction of new surgical techniques likely to make heavy demands on resources over relatively short periods.

In considering the total requirements of haemophiliac patients and the related cost, note has to be taken of -

- (i) the relatively small number of patients,
- (ii) the limited budget available for this purpose.
- (iii) the policy of the government to use blood products made from blood voluntarily donated within the country of use - this is in keeping with WHO recommendations.