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HAEMOPHILIA AND RELATED DISEASES

1. Current activities on this matter largely stand from the paper issued by the Ministry of Health entitled "Care of Persons Suffering from Haemophilia and Related Diseases" for the February, 1965 meeting of Senior Administrative Medical Officers.

This paper:

1. indicates the measures that had been put into effect up to the present to ensure that the medical and social needs of haemophiliacs were properly met;
 2. to find the type of case for which these measures were designed;
 3. suggested that full facilities in the Country should be concentrated at three centres only - Oxford, Manchester and Sheffield: such centres to deal with major treatment, essentially surgical or drastic medical treatment involving the possibility of severe haemorrhage.
 4. recommended that Boards should review the present list of 33 reference centres in the Country, and then, after discussion with teaching hospitals, inform the Ministry of Health of any additional centres that should be added, or of any centres listed that should be deleted. Such centres should be capable of full identification of cases of haemophilia and related diseases, and be prepared to issue identity cards and inform the central registry about the cases diagnosed.
 5. indicated that two other subjects related to the care of persons suffering from Haemophilia and related diseases were under consideration, namely
 - (i) that the organisation of an adequate supply of S.T.E. Haemophilic Globulin was being reviewed, and
 - (ii) that a special inquiry by the Ministry of Education into the need for additional special school accommodation for haemophilic children was being carried out.
2. The Board's Advisers in Medicine, together with Dr. T. H. Boon, were the first body to consider this document, and their comments broadly were as follows:
- (1) that the designation of diagnostic and registration centres can only satisfactory be made following expert evaluation of the facilities offered

by individual hospitals, and including an assessment of the volume of work required to maintain familiarity with the techniques involved in relation to the population served in this respect; and that this evaluation should properly be the responsibility of the medical research council. Arrangements for special training for members of the laboratory staff in some centres might be necessary if the centres lacked the necessary expertise and yet were desirable on geographical grounds.

- (2) that a substantially larger number of major treatment centres required to be recognised on the grounds of practical chemical necessity, and including, pending further deliberations, those at Carlisle and Newcastle upon Tyne.
- (3) that serious consideration should be given to the advantages of establishing combined diagnostic and therapeutic haemophilia centres in sufficient numbers throughout the country to enable the transport to them of patients at higher risk and - or requiring major or surgical treatment to be effected with minimum hazard; and that such centres should, so far as possible, be those already familiar with the cases so referred.
- (4) that the means of providing an adequate supply of human anti-haemophilic globulin, on a national scale, should be energetically sought.

These views were transmitted to Dr. J. N. Twohig, Ministry of Health, in a letter dated 1st April, 1965.

3. The papers and the recommendations from this meeting were next considered at a special meeting which included Dr. T. H. Boon, Dr. George Davison, Dr. J. F. Falls, Dr. A. Inglis, Professor G. A. Smart and Dr. W. Walker. This committee's views may be expressed as follows:

- (1) whilst there was no direct disagreement with the principles contained in the Ministry's paper a shift of emphasis was to be favoured. Contrary to what was implied in the paper it was the emergency complications particularly surgical emergencies which were most difficult to manage, and these were least appropriate for lengthy journeys to the proposed three national centres. It was therefore recommended that a number of regional treatment centres should be increased providing a more local service and that the facilities available should be such as to be capable of dealing with the great majority of elective clinical conditions arising in haemophilic patients. The establishment of comprehensive

units within the Region enabled the staff concerned to become knowledgeable about the patients in their respective catchment areas, and conversely for the patients to gain confidence in staff/^{who}were familiar to them. Nonetheless, it was fully acknowledged that there was a need for one or two national centres which would serve as centres of referral of particularly complicated cases, and also functioned as major centres for research.

In essence, therefore, a special subcommittee favoured the treating of all but the most complicated cases regionally, rather than nationally. (ii) The principal difficulty rising the treatment of haemophilia related to the assurance of an adequate supply anti-haemophilia globulin, and the committee emphasised the recommendations of the earlier meeting that a full investigation ought to be undertaken into the factors relating to the supply HANE on a national basis.

(iii) Three treatment centres might reasonably be provided in the Region - at Newcastle, Carlisle and Middlesbrough (the first two already being designated). Each of these would attract patients from a large enough area to ensure a special case load for the administration of a adequate standard of work, whilst at the same time provide a reasonably local service.

(iv) Once agreement had been obtained for the three centres concerned an approach be made to the Ministry of Health setting forth the revised proposals for the extention in this region of a service of the care of person suffering from Hemophilia and related diseases.

4. Following the correlation of views on their original papers issued in February, 1965 the Ministry issued a second in April, 1966 which modified the earlier paper in that greater latitude was implied in the establishment centres within Regions.

5. Activity concerning the development of the three proposed centres in this Region is as follows:

NEWCASTLE

Newcastle is designated by the Medical Research Council as a diagnostic and reference centre, this status be invested in Dr. T. H. Boon, at the Royal Victoria Infirmary. The service provided links and Dr. Boon as clinician with the Department of Pathology and Professor Heppleston, though it seems that

routine work on coagulation studies is largely in the hands of Dr. Muckle. Within the R.V.I. empire are two other prominent figures in Haematology, viz., Dr. R.B. Thomson and Dr. W. Walker (Paediatric Haematology), but each pursues specific interests and does not always deal in coagulation matters. The counterpart at Newcastle General Hospital is Dr. T. Bird who is a specialist in haematology, but not a clinical haematologist, it seems then as no clinician in this hospital with a particular bent for problems of coagulation. In basic organisation of services there is no cross linkage between the two hospitals.

This sums up the Board's facts of the current situation, but further explanation reveals interesting information. Dr. Bird plainly does not rate Dr. Boon's interest (or indeed perhas even expertise) very highly with reference to Hemophilia and plainly feels the alleged interest has only been stimulated by prospect of possible loss of designated stages. Although Dr. Boon nominally maintains the Hemophilia Register this seems clearly to be in a poor state, being rarely referred to, and (according to Dr. Bird) containing a good deal of erroneous information. Similarly, in the laboratory work on assay of anti-hemophilic globulin, Dr. Bird and his staff are used for taking samples and making estimates. Possibly Dr. Bird's feelings are coloured by his irritation of the fact that - though he knows a good deal about haemophilia -(in fact maybe more than most) - he was not invited to attend the meeting of the Board's officers in July to discuss the care of persons suffering from coagulation disorders. But, looking behind his opinionously fair comments I do not think that he is over impressed by the R.V.I.'s facilities.

There is no doubt that Dr. Bird would be happy to provide a service in the management of coagulation disorders, but as he is not a clinical Hematologist, he has no access to beds and obviously would not wish to appear to intrude upon the province of a physician at the Newcastle General Hospital. He believes that a designated centre in Newcastle is important and is not impressed of the concept of concentration of three national supra-regional centres. In extending this theme he feels that facilities should be concentrated in one hospital, ideally under the control of a single clinical haematologist (he sights Dr. E. K. Blackburn of Sheffield who has his own beds, out-patient clinics, etc.). Short of this, a team of two comprising a clinician and a pathologist (haematologist) should supply the service. He accepts as logical the concept that this might be ~~within~~ R.V.I. based, but thinks it essential that there is

an appropriate laboratory set up to back it; this may well imply the need for more trained staff.

If this were to obtain, the consequence would be progressive diminution of coagulation work in Dr. Bird's Department, but I am sure he is ~~xxxx~~ no empire builder, and though he would regret the trend, he would not oppose it. (Incidentally, it seems that the prospect of loss of this type of work at Newcastle General Hospital did cause the departure of an able senior technician, Mr. Malis, who moved to a better post with Dr. Blackburn in Sheffield).

Dr. Duncan wrote to Mr. Collins, the Royal Victoria Infirmary, on 27th April, 1967 bringing to his attention a copy of a confidential report issued to senior administrative medical officers of all Regional Hospital Boards in England and Wales. This letter asked if Mr. Collins would formally concern from Dr. Boon and Professor Heppleston that they wished the Teaching Hospital to continue to be designated as the diagnostic and registration centre in Newcastle. Mr. Collins replied to the fact that he had discussed the matter with Dr. Boon and Professor Heppleston who had prepared a report supporting the continuance of the Royal Victoria Infirmary as a designated haemophilia centre. Dr. Duncan subsequently replied to Mr. Collins acknowledging the substance of his letter and asked if we could know the names of the specific consultant paediatrician and consultant dental officer designated to take respectively special interest in the care of patients admitted to the teaching hospital as a result of physical blood disorders if, in fact, such designation had been made. Suppose I can discover that we have not received a ~~reply~~ reply from Mr. Collins to this letter.

Dr. Duncan has discussed the whole question of the development of a service for haemophilia in the Region with Dr. Sheila Murray who will be attending the meeting which is to take place in November.