Notes of 2 meetings to discuss Haemophilia Centres in London held on Wednesday 11 February 1970 at Alexander Fleming House, Elephant and Castle London SEL.

PRESENT

Dr Yellowlees (Chairman) Mr Gidden Dr Maycock Mr Hughes Dr Lees Mr Moyes Dr Archibald Mr Gatford * Dr Thomson Miss Davies (Secretary) Dr Obank Professor Hardisty + Great Ormond Street Hospital Dr Dormandy + Royal Free Hospital St Thomas' Hospital Dr Ingram +

* at first (office) meeting only

+ at second meeting only.

INTRODUCTION

A meeting with the Directors of 3 London Haemophilia Centres was preceded by an office meeting at which the situation in London was discussed with particular reference to the Royal Free Centre.

OFFICE MEETING

1. The meeting studied the summary prepared by Dr Obank from replies received from the Directors of the 13 London Haemophilia Centres to his letter of 15 December 1969, from which it was clear that several of the London Teaching Hospital Centres were doing very little work in the treatment of haemophiliac patients.

It was agreed that the Department's policy should be aimed at a reduction in the number of centres in London, possibly by insistence that only 1 of the "Todd pairs" of London Teaching Hospitals should undertake haemophiliac work. Great Ormond Street Hospital would be excluded from the pairing as it dealt exclusively with children. The Lewisham Centre should also remain as it was the only RHB Centre in London.

2. It was thought that there was a need for a major treatment centre in London and that it would be necessary to persuade surgeons that it was essential for major surgery to be performed in a major Haemophilia Centre where adequate support would be available from haematologists experienced in the treatment of haemophilia.

3. Discussion then centred on whether there would be sufficient space at either the Royal Free or St Thomas' for the construction of a major centre. The planning situation at St Thomas' was not known by those present, but Mr Moyes explained in regard to the Royal Free that no provision had been made in the re-building plans because haemophiliac work had only recently been developed there. It would be difficult but not impossible to add another department, so there was a possibility that a major centre could be provided as part of the re-building scheme, or that a separate unit could be built adjacent to the Medical School. Mr Gatford said that the building in which the existing Centre was housed was due to be demolished in 1972 to make way for re-building work and if a new Centre were incorporated in the next phase it would not be ready until 1977. It was not

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known whether the gift of 2000,000 ands by Mr Lawrence Unight was specifically designated for a centre located at the Royal Free or whether any part of it could be used as revenue expenditors. It was however understood that the soney had been put into a Frust Jund and that Dr Dormandy and Mr Knigot were among the Trustoes.

4. It was agreed that the 3 Directors should be asked to speak in suplification of the memorandum which they had submitted prior to the meeting and that their views in regard to a reduction in the number of Centres and the need for a sajor treatment centre might be apportained without revealing the Department's ideas and intertions.

SECOND RECTLIC

5. Mr Moyes and Mr Gatford then withdrew and Professor Mardisty, Dr Dormandy and Dr Ingram joined the meeting. Dr Yellowlees thanked then for their memoreneus and invited each to speak about his/her own Centre.

Dr Ingram said that the work at his Centre at St Thomas' Hospital was increasing 6. steadily. This was partly due to the fact that bacappillison could now be given more and better treatment with the result that patients were attending more frequently, but also because it was becoming more widely known that St Thomas' was particularly active in hacsophiliac work. Or Legram said that he needed an additional Technician to help carry the current workload and a Dopaty Director and a further Pechnician were desirable to enable monitoring of cryoprecipitate material to be undertaken. There was sufficient space for no more then one additional Technician in their present accommodation. Cases requiring major surgery were referred to Oxford because of the shortage of anti-harmophilias material. If therepeutic treatment was to continue to expand as currently indicated there would be a need for further anti-haemophilian material, but Dr Ingrem considered that this need could be not in part if he had sufficient staff to undertake monitoring as he could then regularise the amount of material used. In reply to a question from Dr Maycock, Dr Ingram said that out of the 157 registered cases at his Centre some 20 meeded to attend frequently and another 20 came fairly often.

7. Dr Dormandy said that the development of hassophillae treatment at the Royal Pressince 1964 had imposed a heavy strain on the outpatients' department. They did monitor patients treated with cryoprecipitate and reported the results to the Blood Fransfusion Centre but a Secretary was required to keep the records properly and there was also a need for medical assistance at Semior Registrar level. In reply to a question from Dr Maycock, Dr Dormandy confirmed that the number of registered cases was about the same as at St Thomas' and she thought the same proportion attended frequently and fairly often.

3. Professor Earlisty exclained that at Great Ormond Streat the exphasis was on early treatment of minor bloods in cuildren to prevent crippling. The increase in workload derived from the larger number of treatments being given per patient rather than an increase in the number of patients. At his centre, some 50% of the 69 registered patients sticnded frequently or fairly often. Professor Hardisty also spoke of the need to askey the anti-hasepophilise material and thought that the regruitment of a Technician would relieve his 2 Senior Registrars of the routine part of their present duties.

9. Dr Yelloulees then asked the 3 Directors what their purpose was in getting together and whether they had consulted the Directors of other Centres in London. The Directors explained that they were all members of the Medical Advisory Counittee to the Hastophilis Society and had worked together in the past and ahared a common concern about the development of hastophilise work. They had not discussed the matter with other Directors. They considered that the need for provision of therapeutic treatment on an outpatient basis had increased more than the need for provision for major surgery. Already hastatologists at some of the other London Centres were consulting the 3 Directors and referring petients to them. The Directors thought this trend should continue and might be encouraged by the Department, provided their Centres were adequately staffed to deal with the increasing workload.

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10. The Directors agreed that it was essential for major surgery to be performed where both staff trained in the treatment of haemophilia and adequate antihaemophiliac material were available. The Royal Free dealt with the majority of their own cases, but St Thomas' referred a number to Oxford. There was general agreement that it was desirable to continue to have Oxford as a special treatment and reference centre for the London area.

11. Drs Ingram and Dormandy were then asked about the future availability of accommodation for their work. Dr Ingram said that space had been allocated for a Haemophilia Department in the re-building scheme at St Thomas' and he thought that if necessary he would be able to obtain some addition from part that was not yet allocated. The new department was likely to be available in about 7 years' time. Dr Dormandy said that no space had been allocated in the original re-building scheme at the Royal Free but the Board of Governors had accepted that there was a need for a Haemophilia Department and had agreed to make an area available so that the gift of £100,000 could be used. Dr Dormandy indicated that the total amount of the gift would be spent on building and equipment. Dr Dormandy confirmed that her present accommodation would shortly be demolished but she had been offered alternative space which could be used in the interim.

OTHER ITEMS

12. AVAILABILITY OF HAEMOPHILIAC MATERIAL

Dr Ingram stressed the need for additional material if therapeutic treatment of haemophiliacs was to continue and to expand. Dr Maycock outlined the measures which had been taken to increase production of this material; it was expected that in 3-4 years good supplies of cryoprecipitate etc would be available.

13. TEACHERS IN HOSPITAL

Dr Ingram said that adolescent haemophiliac patients at St Thomas' missed schooling while in the hospital. Therefore, the appointment of a male teacher with special responsibility for haemophiliac patients was desirable.

14. MEDICAL STAFFING OF HAEMOFHILIA CENTRES

Dr Yellowlees explained that it was essential for medical staff below consultant grade to have career prospects, therefore, staff should be appointed to the haematology department and include haemophiliac work in their rotation of duties.

15. Dr Yellowlees then thanked the 3 Directors for attending; the discussion had been very helpful and the Department would take their views into account in considering the problem. The 3 Directors then withdrew.

CONCLUSIONS

16 After further discussion it was agreed that:-

i. It seemed likely that St Thomas' and the Royal Free would in time naturally evolve as the main Haemophilia Centres. Great Ormond Street should also remain in view of its special nature and possibly Hammersmith. The Department could perhaps judiciously speed up the evolution process.

ii. As the 3 Directors had not discussed the matter with Directors of other London Centres, further consultation by the Department would be

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necessary. It was agreed that Professor Dacie of Hammersmith should be among those invited to the Department, together with a representative from the Royal College of Pathologists.

iii. The problem should in due course be referred to Dame Albertine Winner's Joint Working Group.

iv. It was not necessary to issue an amendment to HM(68)8 which set out the arrangements for the care of persons suffering from haemophilia and related diseases.

v. With regard to the Centre at the Royal Free Hospital, it was decided it would be necessary to have a clear indication of the revenue consequences of the development proposed to be built with the money donated by Mr Knight, before agreement was given in principle to the Centre being rebuilt.

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Copies to: Those present (except the 3 Directors) H/H7/7 H/H7/BG3/1