



THE HAEMOPHILIA SOCIETY

P.O. BOX 9 · 16 TRINITY STREET · LONDON, SE1 1DE

Telephone : 01-407 1010

THE THIRD MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY was held on Saturday, 17th March, 1973 at 2.30 p.m. at the Society's Offices, 16, Trinity Street, London SE1 1DE

Those present: Mr. Hunter (in the Chair), Mrs. Britten, Mrs. Hunter, Dr. Kuttner, Mr. Leven, Mr. Polton, Mr. Prothero, Rev. A. Tanner, Mr. Rosenblatt, Mr. D. Caine, Dr. Dormandy, from Groups - Cardiff - Mr. & Mrs. GRO-A Channel Islands - Mr. & Mrs. GRO-A East Kent - Mr. GRO-A and Mr. GRO-A Great Ormond Street - Mr. GRO-A and Mr. GRO-A Leeds - Mrs. GRO-A Lewisham - Mr. GRO-A Manchester - Mr. GRO-A and Mr. & Mrs. GRO-A Oxford - Mr. GRO-A Scotland - GRO-A Southern - Mr. GRO-A GRO-A also present - Dr. I.W. Delamore, Royal Infirmary Manchester Dr. D. Stern, Bournemouth Haemophilia Centre GRO-C

Apologies: Mr. Benfield, Mrs. Cowe, Dr. Davies, Dr. Forty, Prof. Hardisty, Prof. Ingram, Mr. Neil Marten, Mr. GRO-A Dr. Scott Stevenson, Miss Spooner, Dr. Rizza, Dr. Waiter, Prof. Wilkinson

AGENDA

1. Minutes of the previous Council Meeting.
2. Matters arising.
3. Reports from Groups.
4. Applications for Grants from Research Fund.
5. European Committee of World Federation of Hemophilia.
6. Sir Lionel Whitby Award.
7. Annual Report 1972.
8. Holidays and travel abroad.
9. Any other business.

1. Minutes of the previous Council Meeting

The Minutes were signed as a correct record.

2. Matters arising

P.3. Mr. Prothero stated that Dr. Jones' project supported by a grant from the Haemophilia Society was already underway at the Royal Victoria Infirmary Newcastle.

P.4. A letter had been received from Dr. Biggs saying that in her own view the work of the Haemophilia Society and that of the Centre Directors covered such different aspects of the problems of Haemophiliacs that they were best kept separate. If the Council still felt they wished an observer to be present at the next meeting of Directors then the request should be sent to the Chairman Professor Blackburn.. It was agreed that the Secretary should write to Professor Blackburn..

P.5. The name 'Social Worker Fund' has been altered to 'Social Work Fund' and the grant to Dr. Jones at Newcastle had been drawn from this fund.

3. Reports from Groups

Oxford Mr. GRO-A said that he had been asked to act as Chairman for the Cheshire Foundation Hostel Committee in Oxford. This Hostel was to offer accommodation to severely disabled persons reading for a degree at the University or the Polytechnic in Oxford. It would be ready in September 1973, and arrangements were being made for tutors to come to the hostel on necessary occasions. It might be of great benefit to a haemophiliac.

Channel Islands Group The Chairman welcomed Mr. & Mrs. GRO-A from St. Helier, Jersey. It was proposed by Dr. Kuttner and seconded by Mr. Prothero that a Group should be formed of members in the Channel Islands, and unanimously approved. Mr. GRO-A said that some members had agreed to act as Group Officers.

Birmingham & District The members had been concentrating on fund raising for working capital and had sent a donation of £50 to the Treasurer. They were arranging to take part in the Bournemouth Holiday Scheme and were in touch with the Llewisham Group in connection with their caravan scheme.

Cardiff The members of this Group were also busy raising funds. 'A Night at Titic's' was being organised and they had been promised the total proceeds from all the tickets they could sell. A Barn Dance was being arranged. The A.G.M. was to be held on 6th May 1973.

Mr. GRO-A said that many members had been allocated Minis and they were a vast improvement on the Tricycles. He said that the fact that only the owner was allowed to drive the car was a great disadvantage, for instance, when the wife or another driver could have taken the haemophiliac to hospital instead of having to wait for an ambulance. He suggested that the Department of Health & Social Security should be approached to see whether the wife or named driver might be allowed to drive the car for the benefit of the haemophiliac.

Mr. GRO-A and Dr. Tavenner both said that other members had applied and been refused.

It was proposed by Rev. A. Tanner and seconded by Dr. Kuttner that the matter should be taken up with the Department of Health & Social Security. This was agreed..

Mr. Polton said that the Action Committee campaigning for cars for the disabled might take up the matter.

East Kent The newly formed Committee had sent out a questionnaire asking for information from members and ideas for group activities. A Cheese and Wine party was being held in March.

Great Ormond Street Mr. **GRO-A** reported that the A.G.M. had been held last month and a new Committee formed. Mr. **GRO-A** was the Secretary and Mr. C. **GRO-A** the Chairman. £200 had been sent to the Research Fund and it was hoped that the money would be used in work connected with the detection of carriers. It was agreed that this should be brought to the attention of the Medical Advisory Panel.

Leeds The A.G.M. was to be held in October. There had been some apathy among members in attending meetings but fund raising activities were going on.

Lewisham The A.G.M. was to be held on 1st April. The Treasurer had reported a balance in hand of £600, this would probably be used for the holiday caravan. A recent jumble sale had raised the sum of £72. Mr. **GRO-A** said that from the discussion of group representatives which took place before the Council meeting, Lewisham seemed to be the 'odd man out' where the availability of 'cryo.' was concerned. Whereas the average adult dose is 4 to 10 bags at other Haemophilia Centres in Lewisham is was 0. Nobody over 10 years of age is given any at all. Mr. **GRO-A** and Mr. **GRO-A** had arranged to see the Hospital Management Committee at Lewisham Hospital about the matter.

Other members spoke on the problem of adequate availability of cryo. Mr. **GRO-A** of Manchester had contacted the local Blood Transfusion Centre and more cryo. is being provided. Dr. Delamore said that a good understanding had been established with the Blood Transfusion Centre. In Birmingham the relationship between the Hospitals and the Blood Transfusion Centre was not very good and there were many delays in obtaining cryo. Dr. Stern then spoke about both the availability of cryo. and the treatment given to haemophilic patients. Some people were not getting the proper treatment even though they lived near a Centre while others received good treatment and did not live near a Centre. It is not in fact known how the 'system works'. It would appear that matters are greatly helped where the hospital has a good liaison with the Blood Transfusion Centre. He thought that a great deal more information was needed and should be obtained by the Society on the varying conditions of treatment throughout Great Britain. He added that this was not only needed here but also abroad, particularly in view of the increasing amount of foreign travel both for holidays and also for business now that we were in the E.E.C. Dr. Stern felt that the last questionnaire, which had been done hurriedly to obtain information for the Haemophilia Centre Directors' Meeting, was only scratching the surface. A detailed questionnaire was now necessary, so that we may know 'How to organise the Service'.

Mrs. Britten agreed with Dr. Stern that we needed to know a great deal more. She quoted from Sir George Godber's notice to Directors of Centres of 6.3.73 in which mention is made of commercially manufactured concentrates. The Council agreed that the Executive Committee should consider the possibility of another questionnaire.

Manchester: Many social activities were taking place. Executive Committee meetings alternated with informal members meetings often held in their homes. Fund raising has met with good response and it is hoped to raise £1000 from the sale of raffle tickets and to help obtain equipment for the Manchester Royal Infirmary from this venture. As much publicity as possible is aimed at by the Group and posters are displayed in all the main hospitals and the sale of book matches and pens is very good. Mr. **GRO-A** says the Committee would like more active support from the N.W. area. The question of prescription charges had been raised by the members. The Chairman said that the Executive Committee had this matter in hand.

Newcastle & District Dr. Kuttner had received a letter from Mr. A. **GRO-A** saying that he had hoped that the Group would soon be on its feet again. There had been two offers of clerical help. Mr. **GRO-A** had had a very encouraging meeting with Dr. Jones of the Royal Victoria Infirmary.

Scotland Mr. **GRO-A** reported that the 'Stage Coach '72' had raised £6000 and it was hoped that the Society would receive £600. The cheque was to be handed over at a Cheese & Wine party in Edinburgh. The church in Edinburgh to which Mrs. **GRO-D** had belonged was being disbanded and £150 from its funds was to be donated to the Haemophilia Society. It was stated that Dumfries Hospital have supplies of cryo. sent from Glasgow but need a Deep Freeze and will be asking the Society for financial help for this. In order to avoid delay in waiting until the next Council Meeting Mr. **GRO-A** proposed and Mr. **GRO-A** seconded the motion that the Council should approve in advance that a request from Dumfries Hospital for a deep freeze should be granted. This was carried unanimously.

Southern Group Mr. **GRO-A** said that the members thought the Society should look into the problem of blood products and the possibility of organising a central production plant for distribution. Some of the members had thought that concentrates of Factor VIII and Factor IX could not be taken out of the country for use while travelling. Mrs. Britten said this was not so - and was supported by other members of the Council.

4. Application for grants from Research Fund

- (a) Dr. Delamore spoke about his application outlined in the memorandum to Council members. He said that no major developments had taken place in Manchester for about twenty years. In order to improve facilities and expand the work of the Centre, including a possible clinic for Home Treatment, a new system of records was required and the present staff could not cope with all this extra work. A request has been made to the Hospital Management Committee but this is slowly passing through the various committees and will take a long time. Mr. Tanner said he thought that the Society should help now to prevent delay in Dr. Delamore's plans and that the grant could be considered as a 'bridging operation' and would help to make the case for the Health Service to take over. Mrs. Britten proposed that Dr. Delamore be given a grant of £1500 for one year to cover the cost of secretarial assistance for work on Haemophilia. This was seconded by Mr. Polton and approved unanimously. **GRO-C**
- Mr. **GRO-A** said many members had praised the improving service at the Manchester Royal Infirmary.

- (b) Mr. Polton proposed and Dr. Kuttner seconded that the grant of £352.67 should be made to Dr. S.G. Rainsford at Lord Mayor Treloar College for the microscope, details of which were given in the memorandum. This was agreed unanimously.
- (c) Mr. Rosenblatt proposed and Mr. **GRO-A** seconded the proposal that Professor Burke should be given the £33.50 for a starter pack and £27.50 for a refill pack for the Nuvaseal Fissure Sealant not for trials but for active treatment for all haemophiliacs. Mr. Polton said that the Medical Panel was in favour. Mrs. Britten thought that the Society should push for the use of this sealant for all haemophilic children everywhere and reference should be made to it in our next Bulletin. This was agreed unanimously.

5. European Committee of World Federation of Hemophilia

Mr. Tanner said that at the Milan meeting he had been impressed by the idea of a European Committee but since then the organisation had seemed to be very haphazard. Invitations to attend a meeting in Rome had not been received until after the meeting and one for a meeting in Hamburg arrived too late. He thought that we should hold up nominations for a medical and a social welfare expert for the European Committee until problems of organisation had been resolved, terms of reference laid down, and assurance given that money would not be directed away from the World Federation. It was agreed that the minutes of the meetings in Rome and Hamburg should be asked for and that some written future plans should be obtained. Mr. Prothero was asked to write to Avv. Randi of the European Committee and Mr. Tanner said he would take the matter up as a Vice-President of World Federation.

6. Sir Lionel Whitby Award

Mr. Polton outlined a scheme which could be substituted for this award in the future. This would be a prize for work in the medical or allied fields and would be called "The Macfarlane Prize". This was discussed and met with warm approval by the Council. The matter was referred back to the Executive Committee. It was pointed out that any nominations for the Sir Lionel Whitby Award that were submitted this year would be considered.

7. Annual Report - 1972

Mr. Leven proposed and Mrs. Britten seconded the recommendation that the Annual Report be adopted. This was carried unanimously. St. Thomas' Hospital and the Royal Free Hospital had been asked for statements on the use of grants and this addendum will be to hand for the next Council meeting.

Dr. Tavenner said that all the arrangements had now been made for the A.G.M. in Birmingham on 29th April 1973 at the General Hospital. The Council Meeting will be at 2.15 p.m. in the Board Room and the General Meeting will be at 3.00 p.m. in the Lecture Theatre. Tea will be served in the Staff Canteen at 5.00 p.m. Professor Ingram from St. Thomas' Hospital had accepted an invitation to address the meeting.

- 6 -

8. Holidays and travel abroad dealt with under item 3.

9. Any other business

Mr. **GRO-A** said that treatment is available in Jersey for haemophiliacs while on holiday. It was advisable for prior arrangements to be made to replace any cryoprecipitate used in Jersey.

- - - - -

GRO-C

29.4.73