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WITN6392206



THE HAEMOPHILIA SOCIETY

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MINUTES OF THE SEVENTH MEETING OF THE EXECUTIVE COMMITTEE OF THE
HAEMOPHILIA SOCIETY held on 13th November 1975 at the Society's Offices,
16 Trinity Street, London, S.E. 1.

Those present: Rev. Tanner (in the Chair)
Mrs. GRO Mrs. King, Mrs. Stopford
Messrs. Hunter, Knight, Leven, Morris, Polton, Prothero,
Rosenblatt, Dr. Kuttner

Apologies: Mrs. GRO-A Mr. Abrahams

Agenda

1. Minutes of the Meeting held on 9th October, 1975.
2. Matters Arising.
3. Case Committee Report.
4. Honorary Treasurer's Report.
5. Honorary Secretary's Report.
6. Group Matters.
7. WFH and Overseas Matters.
8. Concentrate Campaign.
9. Any Other Business.

1. Minutes of Previous Meeting

The Minutes were signed as a correct record after the following alterations
had been made:-

Page 3, Paragraph 2, Line 1 - Delete 'Lord Mayor Treloar College'
Insert 'Treloar Haemophilia Centre'

Line 3 - Insert 'Lord Mayor Treloar' between
'the' and 'College'

Page 4, Paragraph 3, Line 1 - Delete 'the' and 'of the Lewisham Group'

2. Matters Arising

Page 2 - Mr. Rosenblatt read a draft appeals letter to be sent with copies of 'Journey'. This was approved and it was agreed that Mr. Rosenblatt be at liberty to select suitable recipients, taking into account any suggestions from Committee members.

Page 4 - The young Yemeni boy was now happily settled at a private school, the fees being met by funds from abroad.

Page 5 - The work on the 'Guide for Travelling Hemophiliacs' was being delayed by the lateness of two countries in sending in their returns.

3. Case Committee Report

Mrs. Stopford reported that at the October meeting, two grants had been made. £10 had been paid towards the high costs incurred by a family who were able to keep their son at school only by driving him to and from his Centre, as the Ambulance Service took too long. £15 had been paid to assist with the problems of a newly remarried member. This would be administered by the Local Authority Social Worker who would also provide continuing assistance.

Mrs. Stopford displayed 'Notes for Social Workers' on Haemophilia and explained that similar papers for Careers Officers and DRO's were being prepared, as she felt our existing literature left gaps as far as the information needed by those people was concerned.

4. Honorary Treasurer's Report

The bank balances were:-

Current Account	£6,416.48
Deposit Account	£28,000.00
RFH Account	£422.96

A further £1,000 had been placed on Deposit Account, earning 10½% interest.

As an experiment, a printed appeals letter had been sent out to nearly 1,000 banks, insurance companies, pharmaceutical companies etc. taken from a Kelly's Director, over the last 8-9 weeks. The cost had been in the region of £60-£70 and £400 had been donated so far.

Despite the delay in despatching the Draw Tickets, the response had been good and the change to 20 tickets to a book seemed to be paying dividends. Mrs. King agreed to prepare the tickets for the Draw.

The arrangements were completed for the Christmas Party, with Mrs. King agreeing to purchase the children's presents, Mr. Roseblatt agreeing to see to the organisation of the food, and Mr. Leven agreeing to prepare the competition.

5. Honorary Secretary's Report

In response to a query from the University of Stirling, the Committee agreed that the grant made in support of Dr. Markova's project should be increased to keep up with national salary increases.

Further details of the request of the Association of Haematologists for the North East Thames Regional Health Authority to assist in meeting the costs of setting up the post of Regional Co-ordinator for haemophilia had now been received, as requested by Council. £5,000 would be needed and the work of the Co-ordinator was outlined. The Committee discussed at length the numbers of haemophiliacs in the area, the alternatives, the degree of need and the current problems. Eventually it was agreed to recommend the project to Council, to invite Dr. Jenkins and Dr. Dormandy to address Council.

A letter had been received from Dr. Delamore of the Manchester Haemophilia Centre announcing that the post of Haemophilia Secretary which the Society had funded for 2 years, had now been taken over by the Authority, and acknowledging this was due to our help.

The meeting of the Honorary Officers and WFH Sub-Committee with Travenol Laboratories Ltd. had resulted in help being offered with the Congress, with our News Bulletin and various other matters.

6. Group Matters

Dr. Kuttner reported on the visits he had made and the activities of the following Groups which had been in touch with him:- Birmingham, East Kent, Great Ormond Street, Jersey, Lewisham, North East, Northumbria, North West, Nottingham & Derby, Scotland, Solent, Southern, South Wales. In addition, he had visited Brighton where a new Group was formed subject to approval by Council.

The Honorary Secretary reported on his visit to Northern Ireland for a meeting there to form a Group, subject to Council's approval.

The Manchester Group would seek Council's approval for the donation of £1,000 to purchase equipment for Dr. Evans at the Royal Manchester Childrens Hospital.

7. World Federation of Hemophilia and Overseas Matters

The Honorary Chairman and Honorary Secretary reported on a meeting they had with representatives of American Express, the London Tara and Travenol Laboratories, and the progress with arrangements for the Congress.

It was felt that the WFH Sub-Committee should no longer be expected to handle the arrangements and it was also agreed that a conference co-ordinator should be appointed. The cost would be covered in the registration fees and the benefits were felt to be worthwhile. It was agreed that the Honorary Secretary, as Congress Secretary, should be at liberty to approach possible members for the Congress Committee.

The Haemostasis Club was to hold a meeting on the Wednesday evening of the Congress and it was felt this would be of interest to doctors planning to attend the Congress.

The first meeting of the European Advisory Board was to be held in Amsterdam at the end of the month and Rev. Tanner was attending as the WFH Vice Chairman responsible for Europe. It was agreed to send the Honorary Secretary as the Society's representative.

8. Concentrate Campaign

Publicity for the current situation had been given in recent TV and Radio programmes. A 'World in Action' documentary on the treatment of haemophilia was scheduled for transmission on 1st or 8th December 1975 and it was hoped that a brief for MPs etc. would be completed by then from the comments of the Medical Advisory Panel. The comments received to date were outlined.

9. Any Other Business

The arrangements for the Council and General Meetings were outlined.

It was suggested that Groups be asked not to write to national papers concerning concentrates in view of the forthcoming campaign.

Some discussion took place on the situation with regard to the large amount of work now being handled at the office and it was agreed to put the subject on the Executive Committee Agenda.

GRO-C