



PATRON: H. R. H. THE DUCHESS OF KENT

THE HAEMOPHILIA SOCIETY

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

Telephone : 01 407 1010

MINUTES OF THE MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY
held on Thursday 15 March 1984 at 6.30 p.m. in the Senator Room, The Kennedy
Hotel, Cardington Street, London NW1.

Those present: The Revd. A.J. Tanner, D. Rosenblatt, H.N. Abrahams,
Mrs. M.I. Britten, Mrs. C. Holliday, C. Knight, Dr. L. Kuttner,
Mrs. D. Lewis, K. Milne, D. Watters

AGENDA

- 84.23 Apologies for absence.
- 84.24 Minutes of the meeting held on 9.2.84.
- 84.25 Matters arising.
- 84.26 (a) Seminar Report-back (b) Council Report-back.
- 84.27 Case Committee.
- 84.28 Research Grants Committee.
- 84.29 Honorary Treasurer's Report.
- 84.30 World Federation of Hemophilia.
- 84.31 Co-ordinator's Report.
- 84.32 Any other business.
- 84.33 Date & Place of next meeting.

84.23 APOLOGIES for ABSENCE: Mr. Johnstone and Mr. Prothero.

84.24 MINUTES of the meeting held on 9 February 1984 were, after minor textual amendments, proposed as an accurate record of proceedings by Mrs. Lewis, seconded by Mr. Milne, and agreed unanimously.

84.25 MATTERS ARISING:

(a) Administration Sub-Committee

- (i) Mrs. Watson's replacement: The Co-ordinator was asked to draft and circulate a job specification for Mrs. GRO-D's replacement and to arrange press advertising.
- (ii) Staff Pensions: Following the request of the Council, Mr. Rosenblatt outlined proposals for a staff pension scheme. This will be discussed in greater detail within the Administration Sub-Committee and reported back to the Executive Committee and Council in due course.

(b) Computerization: Mr. Rosenblatt reported that a new piece of equipment was to be evaluated prior to a decision on the actual equipment to be installed.

- (c) A.I.D.S.: The Co-ordinator drew attention to an article in a recent edition of "The Mail on Sunday" in which it was clearly stated that the Society had fulfilled its obligations to its membership. It was agreed that this matter should be left there. The Co-ordinator also reported that it was rumoured that a successful outcome had been achieved in a Press Council action against "The Mail on Sunday" in connection with that newspaper's first piece - "Hospitals Using Killer Blood". It was understood that this would be made public on Sunday 18 March.
- (d) Mothers' Group Booklet: The Chairman reported that he had met briefly with Mrs. GRO-D during the Seminar and after discussion it was agreed that the matter be remitted to the Publicity Sub-Committee for further discussion. Copies of the draft would be circulated to all members of the Executive Committee interested in receiving it. The Co-ordinator was asked to write to Mrs. GRO-D in an attempt to identify more precisely the target group envisaged.
- (e) Blood Products Sub-Committee: Mr. Milne reported that he had received replies from Professor Bloom, Doctors Rizza, Colvin, Forbes and Tuddenham. Reference was also made to Dr. Kernoff's lecture at the Seminar. Following discussion it was agreed that the following priorities should be retained:-
- (i) The establishment of relationships with the Blood Transfusion Service - this to be done initially through Dr. Ala in Birmingham through an early meeting. It was noted that Mrs. Britten wished to be part of this meeting.
 - (ii) Ensure that the B.P.L. development at Elstree be kept on target and that sufficient money be made available to ensure that it can function efficiently when completed.
 - (iii) In connection with (i) above, the future and potential of plasmapheresis should be established.
 - (iv) Additionally, the Society should take advice on steps necessary to ensure adequate supplies of plasma, and
 - (v) We should explore further the involvement of the Society in the recruitment of donors for whole blood and plasmapheresis.
- (f) Future Development of "Groups": The Executive Committee had met informally during the Seminar in Bournemouth and discussed this matter briefly. There it had been tentatively agreed that a new structure was needed for an initial period with proposed new "Groups", the function being that of "area representative" or "area correspondent". This subject was due for fuller discussion at a future date and reporting as appropriate.
- (g) A.G.M. The meeting of the Executive Committee in Bournemouth had discussed the A.G.M. It was agreed (a) that the venue be Manchester and (b) that Dr. Peter Hamilton be invited to address the afternoon session on the theme "Blood Products and their Problems". Dr. Hamilton has now advised that he is available to undertake this. This was noted.

- 84.26 (a) SEMINAR REPORT BACK: The Executive committee paid tribute to all the speakers at the recent Residential Seminar, mentioning in particular the welcome and far reaching content of the lecture given by Dr. Peter Kernoff. Some surprise was expressed that Groups were apparently unaware of fund-raising through 16 Trinity Street and the Co-ordinator was asked to clarify this to Groups in his next mailing. The congratulations of the Executive Committee were expressed by the Chairman to the Seminar Sub-Committee.
- (b) COUNCIL REPORT BACK: A brief discussion was held on Christmas Cards and the Co-ordinator advised that he had already taken steps towards the provision of a religious card for inclusion. Groups would be circulated for potential orders within the next few weeks.

84.27 CASE COMMITTEE: The Co-ordinator reported that the Case Committee had met and wished to present the following recommendations to the Executive Committee:-

- (a) That 50% telephone installation costs be met in respect of a member in the N.W. of England, this being at the request of a social worker.
- (b) That no grant be made in respect of the provision of a soft, safe, play area for a haemophilic child in the South East. This was felt to be contrary to the best interests of the child's development.
- (c) That no grant be made in the case of a social worker's application for a general grant to assist a haemophilic family in the West Midlands.
- (d) That a grant of £50 be made to a member in the Home Counties to assist with mobility problems.
- (e) That a grant of £150 be made to a member in the West Midlands who was facing particularly difficult circumstances.

That these recommendations be approved was proposed by Mr. Milne, seconded by Mr. Knight and agreed unanimously.

It was drawn to the attention of the Executive Committee that there appeared to be some ignorance in Groups, and the wider membership, concerning the amount of money given in grants to members. The Co-ordinator was asked to highlight this at some stage and in the meantime to convey an accurate picture to Groups.

The Case Committee were also asked to give consideration to making grants for limited periods to members following operations, etc. This will be considered.

84.28 RESEARCH GRANTS: The Co-ordinator reported that the Committee had met earlier and wished to make the following recommendations to the Executive Committee:

- (a) UNIVERSITY HOSPITAL OF WALES: (i) Dr. Ian Peake requested underwriting from the Society for the expenses in sending one of his staff to Oxford to work alongside Professor Brownlee for a few weeks, estimated cost being £250. It was hoped that funding would be available from elsewhere. Approval was agreed unanimously, having been proposed by Mrs. Lewis, seconded by Mr. Knight.
- (ii) Dr. Peake had exceeded a grant of £4,590 agreed at the March 1983 meeting of the Council by £345.21. He now requested topping up to meet this extension of his costs brought about by increases in the price of his equipment. Approval was agreed unanimously following a proposal by Dr. Kuttner, seconded by Mrs. Britten.

- (b) PUBLIC HEALTH LABORATORY SERVICES: Dr. Craske had been awarded a grant of £4,332 to engage a part-time worker for two years in connection with his A.I.D.S. Research project (October 1983). He now wished to engage the worker on a full-time basis, keeping funding within the original sum awarded. Approval was agreed unanimously following a proposal by Mrs. Lewis, seconded by Dr. Kuttner.
- (c) ROYAL FREE HOSPITAL: Dr. Tuddenham requested a top-up grant of £70 to enable him to purchase a minor but essential addition to the equipment approved at the December 1983 meeting of the Council. Approval was agreed unanimously following a proposal by Mrs. Britten, seconded by Mr. Milne.

84.29 HONORARY TREASURER'S REPORT: Mr. Abrahams reported that the bank balances were as follows:

Special Deposit Account	£90,000
Ordinary Deposit Account	£10,068
Current Account	£1,157

The following list of notable donations was also tabled:-

	£.	p.	
Speywood Laboratories	250.00		Re: Seminar
Armour Pharmaceutical	750.00		Re: WFH Congress Rio
GRO-D	15.00		Research
In memory of GRO-D	30.00		"
Land Rover UK Ltd	98.65		General
Cutter Laboratories	500.00		Re: Seminar
South Essex Group	47.00		Re: London Marathon
Norfolk & Norwich Group	500.00		General
Mr. & Mrs. GRO-D	500.00		"
Smiths Industries	15.50		"
Cabin Inn, Bowness	70.50		Research
B.P. Group of Companies	500.00		General
Northampton Group	1,500.00		1,250 Research
			250 General
Scottish Group	300.00		General
Mrs. GRO-D	50.00		Research
In memory of GRO-D	28.00		"
Inner Wheel Club of Yiewsley	50.00		"
(In memory of Mr. GRO-D)			
Mrs. GRO-D	130.00		"
Civil Service Sports & Social Club	300.00		"
In memory of Mr. GRO-D	40.00		"
Sheffield & District Group	1,000.00		750 Research
			250 General
North East Group	1,000.00		Research
Cambridge & district Group	500.00		General
South Wales Group	500.00		"
Mrs. GRO-D (In memory of parents)	75.00		Research

84.30 WORLD FEDERATION OF HEMOPHILIA:

- (a) XVI Congress, Rio de Janeiro - The Chairman reported that it had not yet been possible to finalise the UK delegates but the matter would be settled in a short time.
- (b) Bid of 1991 Congress in the UK - Following discussion it was proposed by Mrs. Britten, seconded by Mr. Milne, that the Society were, in principle, in favour of working towards hosting a future Congress in the UK. This was agreed by 6 votes in favour, 1 vote against, with one abstention.
- The Chairman explained that he ^{would} will communicate with Bournemouth Conference Office regarding the nature of the bid which the Society would be prepared to make in Rio de Janeiro to this end. Having made this clear it could be the case that current arrangements for the Co-ordinator's expenses would fall through. The Co-ordinator indicated his acceptance of that situation. It was, however, felt to be of the utmost importance that the Co-ordinator attend at Rio de Janeiro and it was proposed by Dr. Kuttner, seconded by Mrs. Britten that, if present funding arrangements for the Co-ordinator fell through, the Society should meet these costs in full. This was agreed unanimously.

84.31 CO-ORDINATOR'S REPORT:

- (a) It was reported that London Weighting, a component part of the salary of Miss Hawkins and Mr. Watters, had been increased by £57 p.a. with effect from July 1983.
- (b) The Co-ordinator asked the Executive Committee members to note that he had been notified of the following local Group AGM's:-
- (i) Scottish Group - 24 March;
 - (ii) Norfolk & Norwich Group - 2 April;
 - (iii) North Wales Group - 16 June.

84.32 ANY OTHER BUSINESS:

- (a) Mr. Rosenblatt reported that he had received a delightful letter from Mrs. GRO-D following the presentation of the "first instalment" of her retirement gift (£2,000) at the Seminar. There was brief discussion concerning the payment of the balance.
- (b) Mr. Rosenblatt reported that he would be addressing a combined meeting of the Sheffield and Lincoln Groups (in Lincoln) on "insurance" and other themes.

84.33 DATE & PLACE OF THE NEXT MEETING: Thursday 12 April 1984 at 6 p.m. for 6.30 p.m. in the Senator Room, The Kennedy Hotel, Cardington Street, London, NW1.

Approved as an accurate record of proceedings 12.04.84

GRO-C

Signed

Chairman

12 April 1984