



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

THE HAEMOPHILIA SOCIETY

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MINUTES OF THE MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY
held on 9 August 1984 at 6.30 p.m. in the Ludlow Room, Great Western Hotel,
Paddington, W2.

Those present: K. Milne (in the chair); J. Prothero; Mrs. M.I. Britten;
Mrs. C. Holliday; Dr. L. Kuttner; H.N. Abrahams, D. Watters.

AGENDA

- 84.78 Apologies for absence.
- 84.79 Minutes of the meeting held on 12 July 1984.
- 84.80 Matters arising.
- 84.81 Blood Products Sub-Committee.
- 84.82 Case Committee.
- 84.83 Research Grants Committee.
- 84.84 Administration Sub-Committee.
- 84.85 Honorary Treasurer's Report.
- 84.86 World Federation of Hemophilia.
- 84.87 Local Groups.
- 84.88 Co-ordinator's Report.
- 84.89 Any other business.
- 84.90 Date & Place of next meeting.

84.78 APOLOGIES FOR ABSENCE were received from The Revd. A.J. Tanner;
D. Rosenblatt; C. Knight; Mrs. D. Lewis; P. Wetherell;
K. Colthorpe.

84.79 MINUTES of the meeting held on 12 July 1984 were unanimously adopted as
an accurate record of proceedings at that meeting, having been proposed
by Mrs. Britten, seconded by Dr. Kuttner.

84.80 MATTERS ARISING:

(a) R.G. Macfarlane Award: Since the presentation of the Award would
not now take place until mid to late October the draft of the citation
was deferred.

(b) Future development of Groups: The re-drafted paper had been
circulated and, subject to minor textual amendments, it was unanimously
agreed that the paper be circulated to members of the Council for
consideration at the meeting to be held on 15 September. This had been
proposed by Mr. Prothero and seconded by Mrs. Holliday.

84.80 MATTERS ARISING continued

(c) A.I.D.S.: While there was nothing new to report on A.I.D.S. in the U.K., as it affects people with haemophilia, the death of Dr. Luiz Fernando Bare of Brazil (from A.I.D.S.) was noted with deep regret. GRO-A, a haemophiliac, was appointed a Vice President at the XV WPH Congress in Stockholm. The Chairman will convey our condolences to the Brazilian Haemophilia Society in Rio de Janeiro during the forthcoming Congress.

(d) LIVING WITH HAEMOPHILIA: The Executive Committee noted that the Co-ordinator had been in touch with Dr. Jones following the last meeting and that the wording of an appropriate caveat had been agreed mutually.

84.81 BLOOD PRODUCTS SUB-COMMITTEE:

(a) Mr. Milne reported that he had not yet been able to meet the Product Data Services Manager from the Blood Products Laboratory on account of holidays but that they would meet in September.

(b) Mr. Milne also reported that Barry Barber had moved from Cutter Laboratories to Alpha Therapeutics (UK) Ltd.

(c) A brief discussion followed on the involvement of the pharmaceutical companies in the work of the Blood Products Sub-Committee and it was agreed that this should remain on an informal basis.

84.82 CASE COMMITTEE:

Mr. Prothero reported that the Committee had met earlier in the day. They had discussed two applications for financial assistance and wished to make the following recommendations:-

(a) That a grant of £120 be made to a member in the West Country to enable him to purchase a freezer for the storage of cryoprecipitate. In this case it was stressed that the patient concerned did not use cryoprecipitate from choice. The Case Committee also recommended that, if required, the Society would grant up to 50% of the member's telephone installation costs.

(b) That a grant of £50 be made to a member in Scotland to enable single beds to be purchased for two boys. They currently share an old dilapidated double bed and one boy bed-wets.

That the above recommendations be approved was agreed unanimously following a proposal by Dr. Kuttner, seconded by Mrs. Holliday.

84.83 RESEARCH GRANTS COMMITTEE:

The Committee had not met formally and the Executive Committee noted that:

(a) Dr. Preston had not yet put his application in the correct format, and

(b) The Medical Advisory Panel had not completed its responses to the application from Dr. Savidge.

There are no other applications due for consideration at the forthcoming meeting of the Council.

84.84 ADMINISTRATION SUB-COMMITTEE:

The Committee had not met formally. It was noted that Mr. Rosenblatt had eliminated a particular computer from his enquiries and that these enquiries were continuing.

84.85 HONORARY TREASURER'S REPORT:

Mr. Prothero reported that balances were as follows:-

Special Deposit:	£70,000.00
Ordinary Deposit:	£15,068.76
Current Account:	£ 2,643.08

Mr. Prothero is working on a half-year review of finances and hopes to be able to present this at the September meeting of the Executive Committee.

84.86 WORLD FEDERATION OF HEMOPHILIA:

Mr. Milne reported that the Society had now received its copy of THE STATUS AND ATLAS OF HEMOPHILIA WORLDWIDE. It was hoped that further copies would be available in Rio de Janeiro.

Mrs. Britten reported that she had attended a specially convened meeting of the Icelandic National Hemophilia Organization while on a recent visit to that country.

84.87 LOCAL GROUPS: There was nothing to report.

84.88 CO-ORDINATOR'S REPORT:

(a) The Co-ordinator reported that he had recently visited the Supra-Regional Centre at St. Thomas' Hospital, London, and, as a result of the inadequacies he saw in relation to patient facilities, he would be reporting more fully at a future date after he had completed preliminary enquiries with the hospital authorities and appropriate Health Authorities.

(b) The Co-ordinator produced sample Annual Draw Tickets which had been received that day.

84.89 ANY OTHER BUSINESS: No other items had been notified in advance.

84.90 DATE AND PLACE OF THE NEXT MEETING: Thursday 13 September at 6 p.m. for 6.30 p.m. in the Senator Room, The Kennedy Hotel, London NW1.

Approved as an accurate record of proceedings on 13 September 1984

Signed _____

GRO-C

Chairman