



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 11 October 1984 at 6.30 p.m. in the President Room, Kennedy Hotel, London, NW1.

Those present: Revd.A.J.Tanner, Mr.D.Rosenblatt, Mr.K.Milne, Mr.J.Prothero, Mr.H.Abrahams, Mrs.M.I.Britten, Mr.K.Colthorpe, Mr.C.Knight, Dr.L.Kuttner, Mrs.D.Lewis, Mr.D.Watters. *Mrs. Carol Huiday.*

## AGENDA

- |        |  |
|--------|--|
| 84.104 | Apologies for absence                            |
| 84.105 | Minutes of the meeting held on 13 September 1984 |
| 84.106 | Matters arising                                  |
| 84.107 | Treasurer's Report                               |
| 84.108 | Case Committee                                   |
| 84.109 | Research Grants Committee                        |
| 84.110 | Meetings   |
| 84.111 | Blood Products Sub-Committee                     |
| 84.112 | World Federation of Hemophilia                   |
| 84.113 | Salable Items                                    |
| 84.114 | Co-ordinator's Report                            |
| 84.115 | Any other business                               |
| 84.116 | Date and place of next meeting                   |

84.104 APOLOGIES FOR ABSENCE; there were none.

84.105 MINUTES of the meeting held on 13 September 1984: The following amendments were made to the minutes:-  
84.94 (line 2): add "along with Mr Prothero and the Co-ordinator" after "since the last meeting he ..."  
84.98: The word "deposit" should be inserted between "ordinary" and "account" and "special" and "account".

84.106 MATTERS ARISING:

- (a) R.G.Macfarlane Award: Mrs.Britten reported that plans were in hand at the Royal Free Hospital for the reception which would follow the presentation of the R.G.Macfarlane Award to Dr.Tuddenham. It was noted that eight members of the Executive Committee would be attending.
- (b) Society Representatives: The Co-ordinator had circulated a paper developing this theme and members were invited to submit written comments for presentation at the November meeting of the Council.

(c) AIDS: It was noted that there was a new case of AIDS in Scotland. Following the comments of the Mail on Sunday of 23rd September, it was agreed that Paisner and Company should be asked to write a letter to that newspaper refuting their claim that the Co-ordinator had said that their original article in May 1983 was "completely accurate".

(d) Presentation to Mrs Irene Watson: As some members of the Executive Committee could not attend on 15 November it was agreed, if possible, to transfer the presentation to 22 November. It was noted that a total of 12 would attend the event at 7.p.m. at The George Inn, Borough High Street, London, SE1, if held on the latter date.

84.107

TREASURER'S REPORT

(a) Current balances: Mr Prothero reported as follows:-

Special Deposit Account	£70,000
Ordinary Deposit Account	£13,416.74
Current Account	£ 9,523.61

NOTABLE DONATIONS

General Fund

South Wales Group £750, Birmingham Group £500, Courage Charitable Trust £150, Lloyds Brokers £500, DB Godfrey Charitable Trust £25, In memory of **GRO-A** £310, Armour Pharmaceutical £100, C.Byers: Pub Collection £105,

Research Fund

North East Group £500, Northampton Group £1000, Hilltopper County and Western Club £150, Balby Yoga Club £300, Paul Holden: Pub Crawl £125.

Annual Draw Tickets £953.50 - the fastest response ever. We have had to print an additional 40,000 tickets to try to cope with the demand.

(b) The overall financial position: (i) Mr Prothero produced a detailed report on finances to date in the current year. Copies of the report were made available to the Executive Committee and will be circulated to the Council for the November meeting. It was noted that there continued to be a deficit on General Funds and that immediate, as well as long term, measures were required to rectify this position.

/3...

- (ii) While it recognised that Groups could not be expected to expand their fund-raising, they could perhaps make some contribution towards improving the situation in the current financial year. It was agreed that the Chairman would write to Groups.
- (iii) There was detailed discussion of the situation of "Research" funding versus the costs of running the Society and providing a basic service to members. There was a general agreement that the Society had made a greater contribution to haemophilia treatment and care through its overall services than by funding research per se. It was felt that, in future, greater benefit to all would accrue through single funding than from the present arrangement, whereby there were many separate funds. It was agreed that this was a highly desirable way for the future and that the subject should be discussed in greater detail at the November meeting of the Council, bearing in mind the need to allocate funds already received, and earmarked for research, for that purpose over a period.
- (iv) It was proposed that an "external" fund-raising Committee should be set up, comprising people who would not necessarily have any direct involvement with haemophilia, or with the Committee of the Society.
- (v) It was agreed that the Annual Report needed to be more explicit about finance, with an abstract of accounts to make the content more intelligible. The importance of a "social audit" was also emphasised.
- (vi) The benefits accruing from a more aggressive approach to fund-raising were noted, as were the resources available from more sponsorship, lotteries, etc.
- (vii) It was agreed to form a new Finance Committee, consisting of Mr Prothero, Mr Rosenblatt, Mr Knight, Mr Abrahams and the Co-ordinator, which would meet urgently to develop these ideas further. Mr Colthorpe would also join the Group.

The Chairman thanked Mr Prothero for his most thorough report. This was echoed by all present.



84.108 CASE COMMITTEE: The Co-ordinator reported that the Case Committee had met earlier in the day and wished to make the following recommendations to the Executive Committee:-

- (a) A grant of £30 towards the cost of providing a severe haemophilic member with a heating appliance (London)
  - (b) A grant of £10 to assist a single parent purchase an item for his severely haemophilic son (Lancs)
  - (c) A grant of £50 to assist a family with two severely haemophilic sons to cope with hardship (Glos)
  - (d) A grant of £100 towards the mobility needs of a member with severe haemophilia living in SE London
  - (e) A grant of £50 to assist a family facing particular hardship (Yorks)
  - (f) A grant of £80 to assist a single parent family cope with an unexpected financial burden (Scotland)
- That these recommendations be adopted was proposed by Dr.Kuttner, seconded by Mrs Britten, and agreed unanimously.

84.109 RESEARCH GRANTS COMMITTEE

- (a) Dr.G.Savidge, St Thomas' Hospital: Despite a number of letters having been received it was decided to leave the decision of the September Council Meeting as the final decision on this application.
- (b) Dr.Tuddenham: had applied for assistance in connection with the provision of haemophilia treatment in Pakistan. The Executive Committee require further information.
- (c) Dr.Aronstam,LMTC: An application had been received from Dr.Aronstam for a grant of some £3,883 for a Wolf Intra-articular surgery set. After discussion it was decided to recommend that no grant be made since the equipment was not strictly for research purposes.

84.110 MEETINGS

- (a) Centre Directors' Meeting: Mr Milne reported that he and Mr Prothero had attended the Annual Meeting of the Centre Directors held in Cardiff. One of the main outcomes had been the establishment of a Committee to look into the classification of Haemophilia Centres in the UK. The Society had two places available to them on this Committee: those interested were asked to contact the Chairman.
- (b) Haemophilia Nurses Association: Mr Prothero reported on the recent annual meeting of the Haemophilia Nurses Association which he and the Co-ordinator had attended.

84.111 BLOOD PRODUCTS SUB-COMMITTEE: Mr Milne tabled a paper for discussion at the November meeting of the Executive Committee.

/5....

- 84.112 WORLD FEDERATION OF HEMOPHILIA: The Chairman briefly referred to a fund-raising campaign by the Lions for the Haematology Department at King's College Hospital. This had been sent to him by Mrs Picot.
- 84.113 SALABLE ITEMS: Mr Colthorpe's written report was noted and the matter deferred to the Finance Sub-Committee for their consideration.
- 84.114 CO-ORDINATOR'S REPORT
- (a) St Thomas' Hospital: The Co-ordinator reported on conditions at St Thomas' Haemophilia Centre and the financial restraints on the present level of service. It was agreed that a Sub-Committee be set up to explore the position thoroughly. Those serving on the Committee will be Mr Milne, Mr Knight, a patient/relative and the Co-ordinator. This Committee will meet with the Hospital Administrators and Dr.Savidge to assess the extent to which the Society might be prepared to assist.
  - (b) Fund-raising literature: The Co-ordinator reported that he and Mr Knight would be producing drafts for three separate leaflets, targetted to different potential donors.
  - (c) Charities Aid Foundation, AGM: It was regretted that no one would be available to attend the CAF AGM on 31 October 1984.
- 84.115 ANY OTHER BUSINESS
- (a) North Wales Adventure Holiday: Mrs Holliday reported on the financial implications of this venture and explained that the North Wales Group were no longer able to subsidise the event. The Co-ordinator reported that a number of Trusts had expressed an interest in helping and this would be facilitated by the financial report presented by Mrs Holliday.
  - (b) Dr. Aronstam's Book: Haemophilia Bleeding. Mrs Britten reported that she had proof-read this new book which she felt would be most beneficial to people with haemophilia. The publishers had submitted the text with a view, subject to approval, of having the WFH logo on the cover. The Executive Committee, while happy to endorse the publication, did not approve the use of the WFH logo.
  - (c) 1985 Residential Seminar: Mr Knight reported that plans were in hand for the 1985 Seminar. Members were asked to submit suggestions for the Annual Lecture and also to give consideration to a proposal that each delegate makes some contribution towards the cost of the weekend.
- 84.116 DATE AND PLACE OF THE NEXT MEETING - Thursday 8 November at 6.p.m. for 6.30p.m. in the President Room, The Kennedy Hotel, London, NW1.

Approved as an accurate record of proceedings on 8 November 1984

Signed GRO-C Chairman