



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 Thursday 9 February 1984 at 6.30 p.m. in Room 130, The Kennedy Hotel,
Cardington Street, London NW1.

Those present: The Revd. A.J. Tanner, **GRO-A** J.L. Prothero,
Mrs. M.I. Britten, C. Knight, Dr. L. Kuttner, Mrs. D. Lewis,
K. Milne, D. Watters

AGENDA

- 84.12 Apologies for absence.
- 84.13 Minutes of the meeting held on 12 January 1984.
- 84.14 Matters arising.
- 84.15 Blood Products Sub-committee.
- 84.16 Case Committee.
- 84.17 Research Grants Committee.
- 84.18 Honorary Treasurer's Report.
- 84.19 World Federation of Hemophilia.
- 84.20 Co-ordinator's Report.
- 84.21 Any other business.
- 84.22 Date & Place of next meeting.

84.12 APOLOGIES for ABSENCE were received from Mrs. Holliday, Mr. Abrahams,
Mr. Johnstone and Mr. Wetherell.

84.13 MINUTES of the meeting held on 12 January 1984 were unanimously agreed
as a correct record of proceedings at that meeting.

84.14 MATTERS ARISING:

- (a) Computerization/Administration Sub-Committee: Mr. **GRO-A**
reported that the Co-ordinator had seen the ACT Sirius 1 Computer in
operation in a live situation. However, it was agreed that a further
consultation should be held with another independent computer
consultant and a report back be made to the next meeting of the
Executive Committee where the final decision would be taken.
The possibility had arisen of the Society obtaining the lease on the
adjacent small office suite at Trinity Street. It was agreed to
discuss this in the Executive Committee rather than refer the matter
to the Administration Sub-committee. This would mean that the
Executive Committee and other meetings could be held on site once
again with all the advantages and potential saving to be gained thereby.
After a detailed discussion it was agreed that the possibility be
pursued "in principle" and referred back to the Executive Committee as
necessary.

(b) A.I.D.S.: There was nothing new to report. The Co-ordinator advised the meeting that he had asked BBC Radio 4 to correct a statement to the effect that two patients with haemophilia had died as a result of A.I.D.S. A recent paper on A.I.D.S. was also tabled. A.I.D.S. Action Group: The Co-ordinator reported on this Group which, amongst other things, monitored press coverage of A.I.D.S. It was proposed by Mrs. Britten, seconded by Dr. Kuttner, that the Society take out a subscription of £25 p.a. This was agreed unanimously.

(c) Mothers' Group Booklet: The Publications Sub-committee had met but were not ready to report on this matter.

(d) Seminar: The Seminar was reported to be progressing well.

84.15 BLOOD PRODUCTS SUB-COMMITTEE: Mr. Milne's paper had been tabled at the January meeting and was introduced for discussion. In conclusion it was agreed unanimously that until the situation became clearer in relation to blood supplies, it would be wise for the Society to "wait and see". This affected, in particular, issues surrounding A.I.D.S. and it was not yet clear whether a self-sufficiency campaign based on this was justified. The Chairman was particularly concerned about the effect Health Authority budgets might have on future supplies of blood products. This to be investigated further. It was agreed that copies of the Discussion Document should be circulated to members of the Medical Advisory Panel for comment. The Chairman thanked Mr. Milne for his most thorough paper and this sentiment was echoed by those present.

84.16 CASE COMMITTEE: Mr. **GRO-A** reported that the Case Committee had met earlier in the day and discussed eight applications for financial assistance and now made the following recommendations:

- (a) A grant of £150 in respect of the housing requirements of a couple with two teenage severe haemophilic sons. The Committee stressed that they would welcome a further application if the balance were not forthcoming from the other sources who had been approached. (Hamp. Counties) *AS*
 - (b) Formal approval of a 50% telephone installation costs grant (N. Hants). *AS*
 - (c) A grant of £15 in respect of housing removal costs to assist a member who had moved to the Midlands (This is the total requested by a social worker).
 - (d) A grant of £50 towards holiday costs of a family with a severe haemophilic boy.
 - (e) A grant totalling £275 towards holiday/travel costs for a widower (haemophiliac) and his two daughters. This application had received the earnest support of both a social worker and Centre Director.
 - (f) A grant of £50 to help with the travel costs involved in treatment and therapy programmes in respect of a young man with haemophilia and additional problems.
 - (g) A grant of £50 to assist with fares ~~in the care of a member with a rare disorder and associated problems~~ *AS*
 - (h) A grant of £15 to assist with travel costs of a young haemophiliac who has also had recent surgery.
- That the above recommendations be adopted was proposed by Mr. Milne, seconded by Dr. Kuttner and agreed unanimously.

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

- (a) (i) Royal Liverpool Infirmary: This matter, ^{which} was last before the Executive ^{At} Committee in November 1982, concerned upgrading facilities on Ward FY at the Royal Liverpool Infirmary. The local Group, since that time had worked hard and conscientiously to raise funds for this project and had contributed over £5,000 to Society funds, as well as keeping the Society closely informed on developments within the hospital administration. The total cost of the work was now estimated at £9,000 and the local (Merseyside) Group sought leave to contribute 50% of costs, the balance being borne by the Leukaemia Society. This was presented with the unanimous approval of the Grants Committee.
- (ii) Lewisham Hospital: Sister Caffell had asked if sponsorship monies raised by runners in a Prudential Insurance Half Marathon, using the name of the Society, could be used for the purchase of TNS machines for the Haemophilia Centre. This was presented with the unanimous approval of the Grants Committee.
- (iii) London Hospital: Dr. Colvin had written informally to seek the view of the Executive Committee concerning the purchase of a cell sorter. The total cost (£65,000) would be shared between haematology and immunology departments. Haematology had already raised £10,000 towards their share of £32,500 and the purpose of his enquiry was to establish the likely extent of support he might expect from the Society. The Committee felt that for the moment this did not rank as a high priority in grant allocation and that Dr. Colvin should approach the Society when a larger sum had been pledged. That the Executive Committee adopt those recommendations for presentation to the March meeting of the Council was proposed by Mr. Milne, seconded by Mr. Prothero and agreed unanimously.
- (b) Proposed restructuring of the Grants Committee: The Co-ordinator had not been able to draw up a paper to be tabled for this meeting and the Chairman had written to Professor Bloom to obtain his written views. The matter would appear on a future agenda.

84.18 HONORARY TREASURER'S REPORT: In the absence of Mr. Abrahams there was no financial report. Notable donations since the last meeting were as follows:-
Research Fund: E. Jones & Sons (Eltham) Ltd. £15; A.M. Jacob & S.G. Levy £20; Stanley P. Morrison Ltd. £25; Mrs. GRO-D £41.67; Wogan Anniversary Trust £50; Mrs. GRO-D (stocking) £26; Oxford Group (Male Voice Choir Concert) £1,000; Oxford Group £500; In memory of GRO-D £120; GRO-D (stocking) £29.46; Denise Cohen Charitable Trust £25; Vacu-Lug Tyres Ltd. £20; The Crown Hotel, Biggleswade (stocking) £30;
General Fund: Sir Arthur Black Charities £150; AID 1976 Fund £34.50; 124 High Street Club £175; Armour Pharmaceutical (re Seminar) £600; Alpha Pharmaceutical (UK) Ltd. (re Seminar) £250; 21 Signal Regiment RAF Wildenrath £80; Cutter Laboratories (Re: Chairman's visit to India) £629

84.19 WORLD FEDERATION OF HEMOPHILIA:

- (a) XVI Congress - Rio de Janeiro: It was noted that Armour Pharmaceutical have pledged £750 towards Congress costs, Alpha Therapeutics £250, along with a proportion of the £1,000 given annually under Deed of Covenant from Immuno. It was hoped that Speywood and Cutter would also make contributions. It was proposed by Dr. Kuttner, seconded by Mrs. Britten, that the Society meet the balance of costs incurred by the Co-ordinator. This was agreed unanimously. It was further agreed that the Chairman and Co-ordinator liaise on the availability of funding for attendance by representatives in addition to those agreed already.
- (b) Bid for a future Congress in the U.K.: The Chairman and the Co-ordinator will liaise in connection with the formalities involved in this.
- (c) Overseas Sub-committee: The Chairman reported that the Sub-committee had met and that a "shopping list" was awaited from Delhi. Once this was received we would be in a position to consider what, if any, assistance can be rendered by the U.K. An application to Hambro's charitable funds is still outstanding. There is also the possibility of assistance with air freight charges through a member who is a BA pilot.

84.20 CO-ORDINATOR'S REPORT

- (a) A.G.M.: It was unanimously agreed that the A.G.M. be held in Manchester, following a proposal by Dr. Kuttner, seconded by Mrs. Lewis. Members were asked to supply the Co-ordinator with suggestions for topics and speakers. An international figure was suggested.
- (b) Weekend access by the cleaner: Following enquiries from our insurers it was agreed that cleaning at Trinity Street be carried out over the weekend.
- (c) Mr. Frank Smith: It was noted that Mr. Frank Smith had died recently. He was a founder of the International Haemophilia Society, the predecessor of the present Society.
- (d) The R.G. Macfarlane Award: It was noted that the 1982 and 1983 awards were pending.
- (e) Possible Group in Truro: The Co-ordinator reported on enquiries received and subject research on the establishment of a Group in the Truro area. It was agreed in the meantime to invite the instigator of this laudable initiative to attend the Seminar in Bournemouth as guest of the Society. The establishment of further Groups was felt to be inadvisable until after Mr. Prothero's exercise was completed. It was also felt that there was scope for an additional "structure" below that of "Group" which enabled members to meet formally and fundraise on behalf of and in the name of the Society. This will be explored further.
- (f) Duplicator: The Co-ordinator reported that the office duplicator was (a) rarely used and (b) in need of a substantial overhaul. He therefore requested authority to sell it for the best possible price. This was proposed by Mrs. Britten, seconded by Mr. Milne, and agreed unanimously.

84.21 ANY OTHER BUSINESS: There was no other business.

84.22 DATE & PLACE OF NEXT MEETING: Thursday 15 March 1984 in the Senator
Room, The Kennedy Hotel, Cardington Street, London, NW1.

Approved as an accurate record of proceedings 15.03.84

Signed

GRO-C

Chairman