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 Tuesday 6 December 1983 at 6.30 p.m. at the Charles Bernard Hotel, 5 Frognal, London NW3.

Those present:

The Revd. A.J. Tanner, D. Rosenblott, J.L. Prothero, H.N. Abrahams, Mrs. M.I. Britten, C. Knight, Dr. L. Kuttner, Mrs. D. Lewis, K. Milne, P. Wetherell, D.G. Watters

AGENDA

- 83.143 Apologies for absence: Mrs. Holliday, W. Johnstone 83.144 Minutes of the meeting held on 3.11.83. 83.145 Matters arising. 83.146 Case Committee Report. 83.147 Grants Committee. 83.148 Report from Council. 83.149 Honorary Secretary's Report. 83.150 Honorary Treasurer's Report. 83.151 World Federation of Hemophilia. 83.152 Co-ordinator's Report. 83.153 Any other business. 83.154 Date & Place of next meeting.
- 83.143 APOLOGIES for ABSENCE had been received from Mrs. Holliday and Mr. Johnstone.
- 83.144 MINUTES OF THE MEETING HELD ON 3 NOVEMBER 1983: After amending spelling errors at 83.133(b) "plasmapheresis" and at 83.134(c) "haemophiliac" the adoption of the minutes was proposed by Mr. Prothero, seconded by Mr. Milne and agreed unanimously.
- MATTERS ARISING 83.145
- (a) Administration Sub-Committee: Mr. Rosenblatt reported on the Sub-Committee's investigations into computerisation. It was agreed in principle that the Society would benefit from computerisation and the Co-ordinator was asked to view a Sirius computer at an operational site. Mr. Knight submitted a paper from Mr. Johnstone and it was agreed that the Administration Sub-Committee should meet with him to discuss his paper in detail in advance of the next meeting of the Executive Committee if possible.

- (b) A.I.D.S.: While there were no new suspected cases, it was noted that the Cardiff case was now confirmed. The Co-ordinator had tabled a letter from The Mail on Sunday to Paisners. While the entire contents of that letter were open to debate it was felt wise to take up their suggestion to prepare a short letter which the solicitor hoped would appear as an article. The Co-ordinator was asked to draft this and circulate it to the officers for comment.
- (c) <u>Blood Products Sub-Committee</u>: Mr. Milne reported that he had been unable to complete his report in time for this meeting. He did, however, seek permission to meet with the Secretary to the Central Blood Laboratories Authority. It was agreed that Mr. Prothero and Mr. Milne should meet with <u>GRO-D</u>
- (d) North Wales Caravan: In Mrs. Holliday's absence the Co-ordinator reported that the owners of the Caravan Site on which the caravan stood had made an offer of £300 for the caravan as it stood.
- 83.146 CASE COMMITTEE: Mr. Rosenblatt reported that the Case Committee had met and considered five applications for financial assistance. The Committee made the following recommendations to the Executive Committee.
 - (a) A supplementary grant of £10 to a lody with severe vWd Syndrome to enable her to benefit from television.
 - (b) A grant of £60 to assist a member with a problem of mobility, this being conditional upon his social worker obtaining an equal sum from another source.
 - (c) No grant in the case of a new member who required assistance with telephone rental costs.
 - (d) A grant representing 50% of telephone installation costs for a member this being in response to a social worker's request.
 - (e) A grant of £80 to a child who is enuretic as well as haemophilic where there was a need for extra bedding costs which DHSS would not meet.

That those recommendations be approved was proposed by Mr. Knight, seconded by Mrs. Lewis and approved unanimously.
Following comments by Mr. Wetherell, the Co-ordinator was asked to remind Groups of their powers to make grants to people in need.

83.147 GRANTS COMMITTEE:

- (a) The Co-ordinator reported that

 a "top-up" grant of £370 on a grant of £800 agreed at 82.143(d).

 This was in respect of a part-time physiotherapist. Two pay awards had been made in the interim. That this be approved was proposed by Dr. Kuttner, seconded by Mrs. Lewis and approved unanimously.
- (b) The Chairman felt that the time was approaching when we could benefit from a more broadly based Research Grants Committee, along the lines proposed by Professor Bloom. It was agreed that this should be further explored.

- REPORT FROM THE COUNCIL MEETING: There was no special item arising from the Council meeting held on 3 December 1983 but the success of 83.148 the Newcastle Seminar was noted with pleasure.
- HONORARY SECRETARY'S REPORT: Mr. Prothero reported on his visit to the Newcastle Seminar. 83.149
- HONORARY TREASURER'S REPORT: Mr. Abrahams reported that the Research Appeal for £250,000 was now complete. He also introduced on analysis of income from Groups over the past five years. Mr. Abrohams proceeded 83.150 to report on bank balances as follows:-

£7,848.00 Current Account Ordinary Deposit Account £9,795.00 £90,000.00 Fixed Deposit Account

The following notable donations were also recorded in the period since

General Fund: Northern Group £820 (refund re Seminar); Department of

Employment (Redundancy Payment) £142.68 Research Fund: Lewisham Group £800; Merseyside Group £589.28; North West £1,000; Sussex Group £150; Harold Amelan Charity Trust £150; J.B. Cor & Truct Ltd. £10; Bernard Mayers Shipping £10; Adshed Ratcliffe & Co. Ltd. £10; Alexandra Overalls Man. Ltd. £10; Wolton Day Centre £70; P. & J. Yurman £60; G.L. Lockwood £50; PCC St. Andrews Barming Heath £20; Pearl Assurance £125; Exchange Travel (Holdings) Ltd. £20; John Turner & rearl Assurance £125; Exchange 11001 (10101199) Eta. £20; John Turner & Sons (Preston) Ltd. £25; Hourmont Travel Ltd. £10; Guest Motors Ltd. £25; Sons (Preston) Ltd. £25; Hourmont Travel Ltd. £10; Barclays Bank £200; Reliance Gear Co. Ltd. £10; In memory of GRO-A £100; Barclays Bank £200; Richard Pearson Ltd. £5; John Wyatt Ltd. £25; D. Huglin (London) Ltd. £5; Barbour Index Ltd. £100; B. Foster & Co. Ltd. £10; Thomas Tunnuck Ltd. £25; Continho Caro & Co. Ltd. £25; Simon Cumming (disco) £100; Coutts & Co.£50; William Sinclair & Sons Ltd. £25; Townsend-Coates Ltd. £25; Lloyds Bank £100; The Royal Bank of Canada £50; Fisco Products Ltd. £25; F.C. Pollard Charitable Trust £50; National Westminster Bank £250.

Solary Reviews: With the exception of the Co-ordinator's solary, which Solary Reviews: With the exception of the agreed scale, the Administration Sub-was increased by one point on the agreed scale, the Administration Subwas increased by one point on the agreed source GRO-D and GRO-D Committee was delegated to fix solaries for GRO-D for 1984.

- WORLD FEDERATION OF HEMOPHILIA: 83.151
- WORLD FEDERATION OF HEMOPHICIA:

 (a) The Chairman had already reported on his visit to India at the Council The Chairman had already reported the was a very great deal to be done meeting on 3 December. He felt there was a very great deal to be done meeting on 3 December. The Overseas Committee would meet in the near future. (b) XVI Congress - Rio de Joneiro: There was nothing further to report.

CO-ORDINATOR'S REPORT: 83.152

- (a) 1984 Wall-chart Calendars: It was agreed that a number of these charts, bearing the Society's logos, etc. be made available to Centres, Groups and individuals who support us well. Subject to Mr. Knight's discretion, the number should be restricted to 1,000.
- (b) Mother's Group Booklet: The Co-ordinator drew attention to a draft booklet prepared by the Mother's Group at Newcastle Haemophilia Centre under the guidance of GRO-D . At the moment it was thought that this should be produced as a 60 page booklet with coloured cover, etc., but the costs on a 5,000 copy run were likely to be £1 per copy. It was agreed that this matter should be pursued with alacrity through the Publications committee.
- (c) It was agreed that the office would be closed from 23 December to 3 January 1984.
- It was agreed to increase the pay given to the office (d) Cleaner's Pay: cleaner from £2.50 to £3.50 per week.
- (e) Observations from Oxford Group: At the September meeting of the Council, Oxford Group presented a paper on grant allocations. This would be circulated in advance of the next meeting of the Executive Committee for full discussion there.
- (f) Photocopier: The Co-ordinator drew the attention of the Executive Committee to the fact that expenditure was now necessary on the copier in respect of a major service. It was agreed that this should go ahead since it is likely to be some months until the present copier is replaced.
- ANY OTHER BUSINESS: There was no other business. 83.153
- DATE & PLACE OF NEXT MEETING: 12 January 1984 The Senator Room, The 83.154 Kennedy Hotel, NW1.

GRO-C

Vice Charman 12/1/84