

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 11 August 1983 at 6.30 p.m. at the White Hall Hotel, Montague
Street, London WC1.

Those present: The Revd A.J. Tanner, D. Rosenblatt, J.L. Prothero, H.N. Abrahams,
Mrs. **GRO-A**, Dr.L. Kuttner, K. Milne, Mrs. **GRO-A**,
Mrs. **GRO-A**, C. Knight, P. Wetherell
In attendance: D.G. Watters

AGENDA

- 83.96 Apologies for absence.
- 83.97 Minutes of meeting held on 14 July 1983.
- 83.98 Matters arising.
- 83.99 Publicity.
- 83.100 Case Committee Report.
- 83.101 Research Grants Report.
- 83.102 Honorary Secretary's Report.
- 83.103 Honorary Treasurer's Report.
- 83.104 Groups.
- 83.105 World Federation of Hemophilia.
- 83.106 Co-ordinator's Report.
- 83.107 Any other business.
- 83.108 Date of next meeting.

83.96 APOLOGIES FOR ABSENCE were received from Mr. W. Johnstone.

83.97 MINUTES OF THE MEETING held on 14 July 1983:-

- (a) It was noted that at 83.91, dates should read March 9-11.
- (b) It was further noted that the Blood Products Committee had been omitted at 83.84(d). The members of this committee are:
K. Milne; H.N. Abrahams; J. L. Prothero

After the above amendments the minutes were approved unanimously as
an accurate record of proceedings at that meeting.

83.98

MATTERS ARISING

- (a) Redundancy payment - Mrs. GRO-A - it was noted that a claim was being proceeded with and GRO-A would provide the necessary signatures on her return from holiday.
- (b) Sub-committees - The Co-ordinator reported that Mr. GRO-A had indicated an interest in the Case Committee and that Mr. GRO-A had suggested that it would be useful if existing Sub-committee members were to invite appropriate new-comers to serve on their committee. The Chairman invited new members of the Executive Committee to tell him if they wished to serve on any of the Sub-committees.
- (c) Southern Group resolution re: AIDS - The Co-ordinator reported Southern Group had circulated their resolution to all Groups. The Co-ordinator wished to place on record his gratitude to Messrs. Marshall, Bishop and Barber of Alpha, Armour and Cutter respectively, who had all made international checks on the content of the resolution which further substantiated the fact that Germany had not banned the import of US blood products. A statement had been made to all Groups clarifying the situation. Professor Bloom had also been contacted and he did not wish to add to his earlier statement to the Society. It was further reported by the Chairman that Professor Bloom would lead a session on AIDS at the morning session of the Council on 8 October 1983. At Professor Bloom's suggestion, the Co-ordinator was asked to contact Dr. Rizza and Dr. Forbes, inviting them to join the panel.
- (d) Lease: 16 Trinity Street - The Co-ordinator reported that Mr. Hooper of Drivers Jonas had been to inspect the premises and it was anticipated that he would be making a proposal at an early date. It was formally agreed that the Administration Sub-committee be empowered to negotiate and agree terms.
- (e) Research Grants - Ref: Minute 83.88(b) - The Co-ordinator drew attention to a letter from Mr. GRO-A of Tayside Group in which reference was made to Council decisions in 1979/1980 relating to the establishment of a special fund at Ninewells Hospital, Dundee. Having considered this new information it was proposed by Dr. Kuttner, seconded by Mr. Prothero, that Tayside Group be allowed to meet the travel costs of Dr. Tudhope in attending the Centre Directors' Meeting in Oxford on 17 October. This was agreed unanimously. It was further stressed that this was an unique situation which did not set a precedent for other Groups. The Co-ordinator was asked to ascertain balances in this Special Fund and report accordingly to a future meeting of the Executive Committee.

83.99

PUBLICITY - Mr. Knight gave a brief background to this item and discussion ensued. It was agreed that Mr. Knight's original paper be re-circulated to the Executive Committee and that the subject feature as a main agenda item at the October meeting of the Executive Committee.

83.100 CASE COMMITTEE - Mr. Rosenblatt reported that the Case Committee had met earlier in the day and wished to make the following proposals to the Executive Committee:-

- (a) A grant of £150 to a member in the South East who has severe haemophilia A and Hodgkin's Disease. This was made to assist with various costs, principally housing, and was supported by the Centre Director and Social Worker.
- (b) A grant of £35 to a severe haemophilic member in Merseyside to assist with 50% of telephone installation costs. The local authority Social Worker had, under guidance from the Co-ordinator, obtained the other 50% + rental costs from the local authority under the Chronically Sick and Disabled Persons Act.
- (c) A grant of £25 towards the cost of removing a telephone to a new address for a mother with two haemophilic boys. Again, the local authority had met 50% of this cost.
- (d) A grant of £35 to a member in the West Midlands who had recently moved home, this being towards telephone re-installation costs.
- (e) A grant of £25 to assist with exceptional hardship to a member in the South West.

That the above five proposals be adopted was proposed by Mr. Abrahams, seconded by Mr. Milne.

83.101 RESEARCH GRANTS

- (a) The Co-ordinator reported that an application had been received from Dr. F.E. Preston at Sheffield. This had been discussed at the Research Grants Committee earlier in the day and it was agreed that this item should be referred to the Medical Advisory Panel for clarification.
- (b) The Co-ordinator further reported that he had exchanged correspondence with the Oxford Group regarding an article in their Newsletter.

83.102 HONORARY SECRETARY'S REPORT

Mr. Prothero reported that he had recently addressed a meeting of student nurses in Colchester.

83.103 HONORARY TREASURER'S REPORT

	£.	p.
BALANCES:-		
Current Account		943.46
Ordinary Deposit Account		9,385.68
Fixed Deposit Account		90,000.00
Research Fund to date:-		234,172.08

Notable donations:-

Bristol & South West Group £337.90 Research; B.H.G. Ins. Brokers £200 Research; Armour Pharmaceutical £750 Towards N. Wales Adventure Holiday Project; Jan Banford Charitable Trust £500 General Fund; Northern Group £2,500 General Fund.

Petty Cash Account: The Administration Sub-committee had been looking at ways of facilitating petty cash arrangements for the office. It was therefore proposed that an account be opened at the local (Southwark) branch of the National Westminster Bank PLC. Included in the proposal were the normal terms of reference relating to bank mandates, including signatories and a limit of £100 per withdrawal. This proposal, put by Mr. Abrahams, seconded by Mr. Rosenblatt was approved unanimously.

83.104 GROUPS

- (a) The Co-ordinator outlined a proposal from the Northern Group concerning a residential seminar weekend which they proposed to hold in November for haemophiliacs and their families receiving treatment at the Newcastle Centre. It was proposed by the Group to subsidise resident participants to an extent whereby they paid £10 and non-residents would pay £7 (representing adults in both cases). This would require a subsidy of some £2,500 from the Society's funds. There was a detailed discussion regarding this request which culminated in the proposal by Mr. Rosenblatt that approval be given to the request from Northern Group for financial support towards the cost of the proposed residential weekend up to a maximum sum of £2,500. This proposal was seconded by Mrs. GRO-A and 5 votes were cast in favour and 5 votes against. The Chairman utilised his casting vote in favour of the proposal. Mr. Knight, seconded by Mrs. GRO-A put the proposal that the Society continued in principle to support local mini-seminars. This received the unanimous support of those present. The Executive Committee asked that it be suggested to the Northern Group that they may care to consider a representative from neighbouring Groups to take part in the weekend. The expenditure of up to £2,500 will be referred to the Council for final ratification at the October meeting. The Executive Committee went on to discuss the contribution made by Groups to central administration costs and the Research Appeal Fund. This item was deferred for fuller discussion at a future meeting.

83.105 WORLD FEDERATION OF HEMOPHILIA

- (a) It was reported that Cutter Laboratories had pledged funding of up to £1,000 towards the Chairman's expenses in connection with his fact-finding visit to India where, in conjunction with Professor Mannucci he hoped to evaluate the needs of people with haemophilia. Details were yet to be finalised.
- (b) The Chairman reported that Mr. GRO-A was still unwell following his illness in Stockholm. The best wishes of the Society in the UK were expressed.
- (c) It was noted that the Chairman would be in India on the date of the November meeting of the Council. It was therefore agreed that the date of that Council meeting be deferred to Saturday 3 December 1983.

83.106 CO-ORDINATOR'S REPORT

- (a) The Co-ordinator reported on a new growth in Society membership - some weeks as many as 10 new members being added.
- (b) It was reported that preliminary approaches had been made to DHSS with a view to Section 64 funding.
- (c) The Co-ordinator observed that standards had declined substantially at the White Hall Hotel and it was agreed that an alternative central location should be sought.

83.107 ANY OTHER BUSINESS

- (a) Mr. Milne raised questions relating to the forthcoming meeting with the Minister (Lord Glenarthur) on 8 September 1983. After discussion it was agreed that the agenda for that meeting should remain unchanged [see minute 83.55(b)]
- (b) In response to a question relating to Incorporation the Co-ordinator reported that the relevant papers had been filed that day with the solicitors.

83.108 DATE OF NEXT MEETING: N.B. This was changed to Thursday 15 September on account of holidays. Time and venue to remain unchanged.

GRO-C: Alan Tanner

15 September 1983.