

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



THE HAEMOPHILIA SOCIETY

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MINUTES OF THE TWELFTH MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY held on Tuesday 6 April 1982 at 6.30 p.m. at the Society's offices, 16, Trinity Street, London SE1 1DE

Those present: The Revd. A.J. Tanner (Chairman), K.R. Polton, J.R. Hunter, C. Knight, K. Milne, Dr. Kuttner, D. Rosenblatt
In attendance: D.G. Watters

AGENDA

- 82.41 Apologies for absence.
- 82.42 Minutes of meeting held on 11 March 1982.
- 82.43 Matters arising.
- 82.44 Case Committee.
- 82.45 Honorary Secretary's Report.
- 82.46 Honorary Treasurer's Report.
- 82.47 World Federation of Hemophilia.
- 82.48 World Federation of Hemophilia, E.A.B.
- 82.49 World Hemophilia Youth.
- 82.50 Co-ordinator's Report.
- 82.51 Any other business.
- 82.52 Date of next meeting.

82.41 APOLOGIES FOR ABSENCE were received from Mrs. Britten, Mr. Johnstone, Mr. Prothero, Mr. Cleworth, Mr. Abrahams.

82.42 MINUTES of the meeting held on 11 March 1982, which had been circulated in advance were approved unanimously.

82.43 MATTERS ARISING

- (i) Alternative to Nursing Post: The Executive Committee gave unanimous approval to Mr. Polton's suggestion that the pharmaceutical companies be asked to consider making a contribution to costs relating to The Bulletin and the Society's information services. The Co-ordinator and Mr. Polton will liaise on this.
- (ii) Birmingham & West Midlands Group: The Co-ordinator reported on the current situation affecting the caravans which were formerly in the care of the Group. Following discussion it was proposed by Mr. Hunter and seconded by Mr. Knight that the Towyn caravan be placed under the management of the North Wales Group and the Borth caravan placed under the management of the Ladywood Group, both Groups having notified their decision to assume this responsibility. This was approved unanimously.

The Co-ordinator also reported that all the marketable items were now in the custody of the Ladywood Group and it was proposed by Dr. Kuttner, seconded by Mr. Milne, that those goods be donated to that Group for the benefit of the Society. This was approved unanimously.

(iii) Annual General Meeting: The Co-ordinator reported that planning for the A.G.M. was in hand.

(iv) Allocation of Research Appeal: Mr. Polton reported formally that the proposals of the March Executive Committee had received the unanimous approval of the Council.

(v) Draft Annual Report: The final draft of the Annual Report was approved unanimously.

82.44 CASE COMMITTEE: Mr. Hunter reported on the meeting of the Case Committee held earlier in the day and made the following recommendations to the Executive Committee:-

- (1) The Leicester & Rutland Group sought approval of £74 for the purchase of a fridge for a family whose son was on alternate day prophylaxis.
- (2) A grant of £20 towards holiday expenses of a member on the recommendation of his Social Worker.
- (3) A grant of £15 towards bedding and footwear for a member on the recommendation of his Social Worker.
- (4) A grant of £40 towards the total costs (£90) of an adaptation to the car of a member which would enable him to drive again. (The family were providing the balance).

These recommendations were proposed by Dr. Kuttner, seconded by Mr. Milne and approved unanimously.

The Case Committee were also invited, at Mr. Rosenblatt's suggestion, to consider the level of grants made in certain cases and to report more fully to the next meeting of the Executive Committee.

82.45 HONORARY SECRETARY'S REPORT:

- (a) Mr. Polton reported on the application for a grant in respect of computerization of records at Newcastle Haemophilia Centre. After detailed discussion it was agreed unanimously that Mr. Polton should write to the Group advising them that the recommendation of the Executive Committee to the April meeting of the Council be that no further action be taken in the matter until the decisions of the Regional and Area Health Authorities are received by Dr. Jones. It was further agreed that the Co-ordinator should discuss the matter informally with Dr. Jones and also advise him of this decision.

(b) In respect of the St. Thomas' Hospital (London) application for £7,200, being the cost of a refrigerated centrifuge, it was agreed unanimously, after detailed discussion, that the Executive Committee recommend to the April Council meeting that approval be given to this application. It was noted that one Trust had returned a nil decision, but the result of a further application was pending.

(c) Royal Hallamshire Hospital (Sheffield) The Group had requested authority to spend monies held by the Group of up to 50% of the cost of a micro-computer system for the Centre, the total cost being in the region of £1,900 + VAT. This will be recommended to the next Council meeting.

(d) Vice-Presidents: Mr. Polton reported that Professor Bloom had endorsed wholeheartedly the recommendation of the March meeting of Council that Dr. Biggs and Dr. Davies and Professor Ingram be appointed Vice-Presidents of the Society. As a result Mr. Polton had written to those concerned who had responded indicating the honour they felt individually in accepting Vice-Presidencies of the Society. Mr. Polton would now write to Dr. Mayne, Dr. Tuddenham and Dr. Colvin, inviting them to join the Medical Advisory Panel, this suggestion also having received Professor Bloom's approval.

(e) Mr. Polton also reported that he had met with the Duchess of Kent's Lady-in-Waiting earlier in the day and he reported that Her Royal Highness was now out of hospital.

82.46 HONORARY TREASURER'S REPORT: In the absence of Mr. Abrahams, the Co-ordinator presented the Honorary Treasurer's Report as follows:

(a) Balances:	Current Account	£2,762.14	
	Ordinary Deposit A/c	£27,065.72	
	Special Deposit A/c	£51,000.00	
Research Fund:	1979/1980/1981	£130,355.39)	
	1982 to date:	£42,118.72)	TOTAL to date: <u>£172,474.11</u>

Notable donations since last meeting:

Midshires Building Society £250 Research; Colchester Group £500 Research; Southern Group £1,150 Research, £100 General; Lewisham Group £500 General; Ladywood Group £300 Research; North Eastern Group £750 Research, £250 General; Northern Ireland Group £1,000 Research, £1,000 General; Merseyside Group £1,173.74 Research; Northern Group £9,000 Research; South Wales Group £200 General; Lincoln & District Group £346.56 Research; Sir Walter Raleigh Lodge Benevolent Fund £70.00 General; Waltham Abbey Carnival Association £25.00.

(b) The Executive Committee also received Mr. Johnstone's paper concerning the Centralisation of Group Bank Accounts and Mr. Abraham's comments. It was agreed that this subject could be discussed more fruitfully when both were present and, accordingly, it was deferred to the May meeting.

82.47 WORLD FEDERATION OF HEMOPHILIA: The Chairman had asked the Co-ordinator to explore methods of payment of individual WFH membership fees following the last meeting. In turn the Co-ordinator and the Treasurer had discussed the matter and the Co-ordinator reported that they wished to recommend that people in the U.K. be offered two methods of payment:-

- (i) that the individual make appropriate arrangements through their own banks for the subscription to be submitted to Montreal in dollars - this was the cheap, but complicated method. As an easy alternative - but more costly:-
- (ii) that the Society make the arrangements on behalf of the individual applicant, but in such cases there would be a handling charge - e.g. at today's rate of exchange \$30 = £17, but the Society would impose a charge of £5 which would also include membership of the Society in the U.K.

After discussion it was proposed by Mr. Milne, seconded by Mr. Rosenblatt, that these alternatives be put to potential WFH members. This was agreed unanimously.

82.48 WFH - EUROPEAN ADVISORY BOARD - There was no report.

82.49 WORLD HEMOPHILIA YOUTH - There was no report.

82.50 CO-ORDINATOR'S REPORT

1. Collecting Boxes and Flag Day Stickers - Approval was given for expenditure up to £400 in this connection.
2. Extension of Mrs. Watson's Working Week - Deferred.
3. Alternative Office Premises - Discussion took place and it was resolved that the search for new offices continue, approaches to be made to various London estates. It was also felt that, should suitable premises emerge, we should be prepared to move prior to expiry of our present lease. Dr. Kuttner pointed out the advantage of having premises which could also accommodate Council meetings.
4. Solent Group: It was resolved that members in the area covered by this Group should be written to expressing the hope that they link up with the Southern Group since the Group itself has been inactive for some time.
5. National Council of Voluntary Organisations: It was proposed by Mr. Hunter, seconded by Mr. Milne, that the Society seek membership of NCVO at an annual cost of £30. This was agreed unanimously.
6. Life Membership: The Co-ordinator explained that a number of enquiries had been received recently. In discussion with Mr. Abrahams both had felt such memberships to lack the benefit to the Society of Deeds of Covenant. The matter was deferred for fuller discussion at the May meeting.

82.50 CO-ORDINATOR'S REPORT continued

7. Bristol & South West Group: Some members were experiencing difficulties with the Centre following a decision to withdraw cryoprecipitate from the treatment programme. It was resolved that Mr. Polton would write appropriately to Dr. Scott, the Centre Director.
8. Lincoln & District Group: The Co-ordinator reported that Mrs. Would had resigned as Chairman of this Group. An appropriate letter of thanks will be sent to her for her work.
9. Seminar feed-back: The Co-ordinator reported this to be coming in but only very slowly. Everyone appeared to have been inspired and felt the weekend most worthwhile.

82.51 ANY OTHER BUSINESS: There was no other business.

82.52 DATE OF NEXT MEETING: Thursday 13th May 1982.

N.B. JULY meeting will be on WEDNESDAY 14th JULY.

GRO-C

13 May 82.