

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



THE HAEMOPHILIA SOCIETY

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MINUTES OF THE FIFTH MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY held on Thursday, 9th September 1982 at 6.30 p.m. in Seminar Room 6NE, St. Thomas' Hospital, North Block, London SE1 7EH

Those present: The Revd. A.J. Tanner (Chairman), K.R. Polton, J. Hunter, H.N. Abrahams, J. Prothero, W. Johnstone, C. Knight, J. Ritchie, K. Milne, Mrs. M.I. Britten, Dr. L. Kuttner.
In attendance: D.G. Watters

AGENDA

- 82.110 Apologies for absence.
- 82.111 Minutes of meeting held on 12 August 1982.
- 82.112 Matters arising.
- 82.113 Case Committee Report.
- 82.114 Grants Committee Report.
- 82.115 Honorary Secretary's Report.
- 82.116 Honorary Treasurer's Report.
- 82.117 World Federation of Hemophilia.
- 82.118 WFH - European Advisory Board.
- 82.119 World Hemophilia Youth.
- 82.120 Co-ordinator's Report.
- 82.121 Any other business.
- 82.122 Date & Place of next meeting.

82.110 APOLOGIES FOR ABSENCE - there were none.

82.111 MINUTES OF MEETING held on 12 August 1982: after the following amendment at 82.100(b), line 2, to read "... Hereditary Telangiectasia ... not a blood disorder" the adoption of the minutes was proposed by Dr. Kuttner, seconded by Mr. Milne and approved unanimously.

82.112 MATTERS ARISING:

(a) Oxford Lottery: In the absence of Mr. Rosenblatt, the Co-ordinator reported that satisfactory written confirmation had been received in accordance with the decision of the last meeting of the Executive Committee and instructions had been issued for the first two lotteries to proceed on the basis of the income being received by the Society. It had not, however, been possible to call a General Meeting of the Oxford Group since certain irregularities had arisen and in connection with which the Chairman and Co-ordinator would be attending a meeting of the Oxford Group Committee on Monday 13 September. It was further proposed by Mr. Prothero, seconded by Mr. Milne that those Officers attending the meeting be empowered to take whatever steps were felt necessary regarding the activities of the Group.

82.112 MATTEES ARISING continued

(b) Meeting with the Minister: Mr. Milne reported that he and the Co-ordinator had met with representatives of the DHSS on Tuesday, 7th September and that they had discussed the development of the Blood Products Laboratory at Elstree; prescription charges; Mobility Allowance and possible DHSS funding. In discussion the Executive Committee accepted that it would be unwise ^{to the time being} to pursue further the question of prescription charge exemption, welcomed the fact that the Co-ordinator had arranged to meet a senior representative of the Minister for the Disabled in connection with Mobility Allowance and noted the possibility of funding being available for assistance with new headquarters premises.

(c) Centre Directors Meeting: It was noted that Mr. Milne would attend on behalf of the Executive Committee on Monday 13 September.

(d) Haemophilia Nurses Association Symposium: It was noted that Mr. Prothero would attend on behalf of the Executive Committee on 20/21 September.

(e) Factor VIII Charity: The Co-ordinator reported that this charity now had £4,000 available for disbursement and that the charity had written to two Haemophilia Centres asking them to make application. The Chairman noted that deliberations about the future relationship between the Society and Factor VIII had not been resolved.

(f) Armour Pharmaceutical: Mr. Prothero reported that he had met with Mrs. Dawn Lewis as reported at the last meeting.

82.113 CASE COMMITTEE REPORT

Mr. Hunter reported that the Committee had met earlier in the day at 16 Trinity Street and wished to make the following recommendations to the Executive Committee:

- (a) A grant of £98 to a patient who had to attend for orthopaedic assessment at St. Thomas' Hospital.
- (b) A grant of £50 be made to a family in severe hardship based upon strong recommendation of the local Group.
- (c) A grant of £25 be made to a young haemophiliac recently left school who was having difficulty settling into life at home and was incurring high travel costs to his Centre for treatment.
- (d) That no grant be awarded in respect of telephone rental costs.

That these recommendations be approved was proposed by Mr. Milne, seconded by Mrs. Britten and agreed unanimously.

Mr. Hunter further advised that there were two cases awaiting further investigation.

82.114 GRANTS COMMITTEE REPORT

The Chairman reported that the Grants Committee had met earlier in the day at 16 Trinity Street and considered the following applications:-

- (a) (i) Derbyshire Royal Infirmary: Dr. Mitchell had applied for assistance with a word-processor. The Co-ordinator was asked to investigate her needs more precisely.
- (ii) Re: Symposium of factor VIII/von Willebrand factor: Two applications had been received for assistance with travel costs to this Symposium in San Diego. It was agreed unanimously that the Society should not assist in either case and should recommend accordingly to Council.
- (iii) Royal Free Hospital: An application had been received from Mrs. Miller at the Royal Free Hospital for a grant of £750 to assist with the costs involved in making a video recording of her group-work with various groups of haemophiliacs. Unanimous approval was given to a positive recommendation being made to the next meeting of the Council.
- (iv) Dr. Hill's application: The Executive Committee gave further consideration to this application which had been agreed in the sum of £6,934 in September 1981. Since then the local Birmingham Social Services Department had said that this could not establish the post of a social worker for the Haemophilia Centre unless some £16,000 was available in the first year. It was decided unanimously that, subject to consultation with Dr. Hill, a final sum of £8,000 (being half the revised sum requested) be made available to Dr. Hill, subject to arrangements being made for a part-time appointment or the balance of funding being available from elsewhere.
- (v) Royal Free Hospital: It was decided that an application from Dr. Tuddenham in respect of a Japanese research fellow who he hopes will work on either (a) factor VIII related antigen multimers in vWd and other disorders, or (b) purification of coagulation factors VII~~X~~ and XI for use as immunogens in raising monoclonal antibodies, be referred to the Medical Advisory Panel for urgent consideration at the September meeting of the Council.
- (b) The Grants Committee had also discussed the draft application form in the light of Professor Bloom's comments and the Chairman reported that these, and other changes, would now be incorporated into a final draft and referred back to Professor Bloom for final comment.

82.115 HONORARY SECRETARY'S REPORT: Mr. Polton had nothing to report.

82.116 HONORARY TREASURER'S REPORT:
Amendment to Honorary Treasurer's Report (82.103) August meeting:-

Re: Research Fund

As at the last meeting the fund balance was in fact £66,536 and NOT £67,487.

Grants which were payable pending invoices etc. and which have been taken into account in arriving at £67,487 should be amended as follows:-

delete St. ~~Thomas~~^{James} Hospital, Leeds £1,000 - This had been paid

St. Thomas' Hospital balance should be £16 ~~not~~ £307

Cambridge Dept of Veterinary Medicine £2,742 (this was omitted in error from previous report)

Subject to the above amendment there is nothing of any further significance to report relating to the Research Fund since the last Executive Meeting other than amount raised to date (see below).

BALANCES:

Current Account	1,501.09
Special Deposit Account	61,000.00
Ordinary Deposit Account	502.51

Research Fund has raised to date: £186,232.14

Notable donations: Brookdale Brealey £223.45 General Fund
Whitcroft Ltd. £70.00 Deed of Covenant

82.117 WORLD FEDERATION OF HEMOPHILIA: The Chairman reported on his successful visit to Budapest for a useful Congress and meeting of WFH Executive Committee. He mentioned a particularly useful session on haemophilia addressed by Dr. Tony Britten and Dr. John Cash.

82.118 WFH - EUROPEAN ADVISORY BOARD: Mr. Prothero reported that changes were likely with EAB and that they would be announced in the future. Mr. Johnstone raised the question of representation of Groups at the forthcoming Congress in Stockholm. It was clarified that there would be a total of three delegates appointed to represent all 28 Groups and that this would be the full extend of Society money - from either local or national sources - which could be spent in this way. The Society's total representation is therefore 6 - 3 representing local Groups plus 3 who will represent the national membership of the Society.

82.119 WORLD HEMOPHILIA YOUTH: The Chairman formally welcomed Mr. Ritchie back from his visit to the USA. The Co-ordinator will endeavour to set up a full meeting of the WHY Committee later in the autumn/winter.

82.120 CO-ORDINATOR'S REPORT: The Co-ordinator reported as follows:-

(a) Birmingham West Midlands Group: The Chairman undertook, in co-operation with the Co-ordinator, to call a General Meeting of those members of the Society in the Birmingham and West Midlands area and to liaise with the Ladywood Group regarding this.

(b) Charities Aid Foundation Annual Meeting: This will be held on 28 October in London.

(c) Pharmaceutical Companies: None of the companies were in a position to consider funding The Bulletin as an alternative to the nursing post.

(d) Seminar 1982: The recommendations, etc, from this would be an agenda item at the next meeting of the Executive Committee.

(e) Annual Draw: It was noted that the Annual Draw on 23 October would be hosted by the North West Group. Mr. Hunter and Mr. Polton indicated a willingness to attend.

(f) Solent Group: It was approved that unless Solent Group provide documents required by the Society before the date of the next Committee Meeting, the Group be suspended. The Co-ordinator to write.

82.121 ANY OTHER BUSINESS:

Seminar 1983 - Mr. Prothero reported that the Seminar Committee had now settled on a venue in Bournemouth for the 1983 Seminar. This was approved unanimously. Mr. Prothero also gave a brief outline of the Committee's provisional programme for the weekend.

82.122 DATE & PLACE OF NEXT MEETING: The Seminar Room at The Katharine Dormandy Haemophilia Centre and Haemostasis Unit at the Royal Free Hospital, Pond Street, NW3 2QG at 6.30 p.m. on Thursday 14 October 1982.

GRO-C: Tanner

14 October 1982