



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 15 September 1983 at 6.30 p.m. at the White Hall Hotel, Montague  
Street, London WC1.

Those present: The Revd. A.J. Tanner, Mrs. M.I. Britten, Mr. W. Johnstone,  
Dr. L. Kuttner, C. Knight, K. Milne, Mrs. D. Lewis, P. Wetherell  
In attendance: D.G. Watters

## AGENDA

- 83.109 Apologies for absence.
  - 83.110 Minutes of meeting held on 11 August 1983.
  - 83.111 Matters arising.
  - 83.112 Report of meeting with Lord Glenarthur.
  - 83.113 Case Committee Report.
  - 83.114 Research Grants Committee.
  - 83.115 Honorary Secretary's Report.
  - 83.116 Honorary Treasurer's Report.
  - 83.117 Groups.
  - 83.118 World Federation of Hemophilia.
  - 83.119 Co-ordinator's Report.
  - 83.120 Any other business.
  - 83.121 Date of next meeting.
- 83.109 APOLOGIES FOR ABSENCE: D. Rosenblatt, H.N. Abrahams, Mrs. C. Holliday,  
J. Prothero.
- 83.110 MINUTES of meeting held on 11 August 1983, which had been circulated  
in advance, were agreed unanimously as an accurate record of proceedings  
at that meeting.
- 83.111 MATTERS ARISING
- (a) Lease, 16 Trinity Street: Mr. Rosenblatt reported that Messrs  
Drivers Jonas had proposed that our lease with Trinity House be  
renewed at £3,500 p.a. Subsequent negotiations had reduced this  
to £3,300. It was agreed that we proceed to secure the lease for  
a further five year term at this amount subject to the advice of our  
solicitors.
  - (b) Chairman's trip to India: Plans for this trip, which the Chairman  
will undertake in his role as Chairman of the World Federation of  
Hemophilia, under the auspices of Cutter International funding,  
are proceeding. The Chairman emphasised that the principal objective  
of his visit was to open up treatment opportunities in India, and that  
the Society in the UK would not be committed to any expenditure in  
addition to that already provided.

(c) Sub-Committees:

Mr. Johnstone reiterated the point made at 93.98(b) in this connection.

83.112

REPORT OF MEETING WITH LORD GLENARTHUR: The Chairman outlined the content of the meeting held with Lord Glenarthur and his officials on 8 September. The Society was represented by the Chairman, Honorary Secretary and the Co-ordinator. The discussion had centred around:-

- (1) Self-sufficiency in UK blood products: While it was clear that the Government had committed funds (£21m) to the development of BPL Elstree to extend their premises, it was felt that self-sufficiency in two years time, while an ideal, seemed unlikely to be a reality, not least due to the difficulty which could be foreseen in procuring adequate supplies of plasma.
- (2) Imported Factor VIII concentrates: The Society and the Department agree that factor VIII concentrates must continue to be imported from the USA. Any other course of action could only lead to people with haemophilia being exposed to even greater risks through lack of concentrates for bleeding episodes. This is still the view held by both parties in the knowledge of one recorded death at Bristol which was suspected on the day of the meeting.
- (3) AIDS: The Chairman outlined the concern felt by the Society that HMG had not earmarked funds for AIDS research in the UK. Lord Glenarthur had pointed out that while no monies had been specifically earmarked for AIDS research to date, valuable work was taking place on collation of available data from around the world. A Working Party has been established under the auspices of the Medical Research Council. We were assured that funds would be made available and that HMG were most anxious to encourage studies which would lead to the eradication of AIDS.

The Executive Committee went on to consider AIDS in the UK more generally and in particular the fact that the first AIDS-related death had now been confirmed in a 50+ year old man in Bristol. The Co-ordinator presented the view that this fact would eventually reach the press and that the Society should immediately issue a statement to all members advising them of the death and pointing out all the steps taken so far by the Society in relation to AIDS. It was agreed that this would place people with haemophilia in a position of some strength when the subject hit the pages of the popular press and would serve to prevent some of the panic which followed the May reports in the media. Mr. Knight and the Chairman undertook to oversee the production of this leaflet and attempts would be made to get it out with all possible speed. In the meantime the Executive Committee would continue to keep a close watch on developments in the UK.

83.113 CASE COMMITTEE: The Co-ordinator reported that the Case Committee had met earlier in the day and presented the following recommendations to the Executive Committee:-  
RATIFICATION was sought for action already taken in the following two cases:  
(a) A grant of £30, plus travel warrant, to enable a family attend prenatal diagnosis in London. The application was made on behalf of the family by the Centre Director and his social worker.  
(b) A grant of £60, plus travel warrant, to enable a mother and her three year old son to attend a holiday at the North Wales caravan. This grant was sought by Centre staff due to problems which had emerged in the family.

The following applications were presented:

- (c) A grant of £50 to a Scottish family to assist with hardship on the recommendation of the local Group.
  - (d) A grant of £30 to assist a family with two haemophilic sons in the North of England. One of the boys had a prolonged spell in hospital and fares had brought the family into financial difficulties. The application was supported by the Centre Social Worker.
  - (e) That no grant be made in respect of an application by a London haemophiliac where circumstances did not merit such an award.
- That the Executive Committee approve these recommendations was proposed by Mr. Milne, seconded by Mrs. Lewis and approved unanimously.

83.114 RESEARCH GRANTS COMMITTEE:  
The Chairman reported that the Committee had met and discussed applications. The following recommendations were made to the Executive Committee:

- (a) That Dr. Preston's application for a grant of £1,116.70 in respect of work on the basic structure of factor VIII be approved.
  - (b) That in response to an application from Dr. Craske (PHLS) for a grant totalling £10,189, relating to AIDS research, a grant should only be made in respect of the clerical officer. The Committee had regard to the Council's policy regarding computers (which comprised the balance of the application) and did not feel able to recommend this to the Council.
  - (c) That a grant for Dr. Tuddenham for £17,623 be investigated more closely before a recommendation is made to the Council.
- After discussion of each application the proposals were agreed nem con, having been proposed from the Chair.

83.115 HONORARY SECRETARY'S REPORT: On behalf of Mr. Prothero, the Co-ordinator reported that the contract for travel to the XVI WFH Congress in Rio would be awarded to American Express Travel, whose quotation for the package was the cheapest. This was ratified by the Executive Committee.



83.116 HONORARY TREASURER'S REPORT

BALANCES:

	£. p.
Current Account	1,377.00
Ordinary Deposit Account	9,795.00
Fixed Deposit Account	90,000.00
Research Fund to date:	234,453.00

Notable donations:-

Whitecroft Ltd. £70 Deed General fund; Various in memory of **GRO-A**  
 £68.80 Research; Mrs. **GRO-A** in memory of mother, £130.  
 The Chairman reported that since the last meeting the Honorary Treasurer  
 had written to him expressing his concern following the discussion at  
 83.104(a) concerning the Northern Group Seminar. This was noted.

83.117 GROUPS: Mr. Milne reported that he had attended the AGM of the  
 Colchester District Group. The Co-ordinator introduced a motion from  
 the North West Group which proposed that the Society should provide  
 Society T-Shirts on a national basis, thereby reducing unit costs on  
 the larger orders which would be possible. This was agreed by the  
 Executive Committee and the Co-ordinator was asked to arrange this.

83.118 WORLD FEDERATION OF HEMOPHILIA - There were no WFH matters to report.

83.119 CO-ORDINATOR'S REPORT: It was reported:-  
 (a) Fund-raising letters are now going out.  
 (b) The October meeting will be held at the Cora Hotel in a lounge and  
 the main agenda item will be PUBLICITY.  
 (c) The Co-ordinator asked the Executive Committee to consider changing  
 Mrs. Watson's job-title from 'Assistant Secretary' to 'Personal  
 Assistant to the Co-ordinator'. This was agreed unanimously.  
 (d) The Co-ordinator reported that Miss Hawkins had completed her two  
 month probation period to his satisfaction and he recommended that  
 her employment be confirmed. this was agreed unanimously.

83.120 ANY OTHER BUSINESS: There was none.

83.121 DATE OF NEXT MEETING: Thursday 13 October 1983 at THE CORA HOTEL,  
 Woburn Place, London WC1 at 6 p.m. for 6.30 p.m.

**GRO-C**

1983.

13 October