



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 3rd November 1983 at 6.30 p.m. in the Senator Room, The Kennedy Hotel,
Cardington Street, London NW1

Those present: The Revd. A.J. Tanner, D. Rosenblatt, J.L. Prothero,
H.N. Abrahams, Mrs. M.I. Britten, Mrs. C. Holliday,
Mr. W. Johnstone, Mr. C. Knight, Mrs. D. Lewis, Mr. K. Milne
In attendance: D.G. Watters.

AGENDA

- 83.131 Apologies for absence.
- 83.132 Minutes of the meeting held on 13.10.83.
- 83.133 Matters arising.
- 83.134 Case Committee.
- 83.135 Grants Committee.
- 83.136 Honorary Secretary's Report.
- 83.137 Honorary Treasurer's Report.
- 83.138 Groups.
- 83.139 World Federation of Hemophilia.
- 83.140 Co-ordinator's Report.
- 83.141 Any other business.
- 83.142 Date & Place of next meeting.

83.131 APOLOGIES for ABSENCE were received from Dr. Kuttner and Mr. Wetherell.

83.132 MINUTES of the meeting held on 13.10.83, having been circulated in advance, were agreed unanimously as an accurate record of proceedings, after minor textual amendments.

83.133 MATTERS ARISING:

- (a) Publicity: The Co-ordinator reported that, following the October meeting, the analyst had spent time in the office and his report was tabled. It was agreed that this report should be studied by the Administration Sub-Committee who should report back to the December meeting. Mr. Johnstone and Mr. Knight would also consider the report and be prepared to report additionally on that and on photocopying equipment.

- (b) A.I.D.S. There had been no significant developments since the last meeting. It was noted that the Minister (Kenneth Clarke) had committed himself to self-sufficiency in blood products in a recent radio broadcast. In the same broadcast he had also stated that in the meantime it was in everyone's best interests to continue the importation of blood products. An article in The Times of 3 November regarding the free supply of blood to private hospitals was drawn to the attention of the Executive Committee. The Co-ordinator reported that it was anticipated that a charge would be applied in the near future and it was hoped that this income would be used to fund plasmapheresis or some other aspect of self-sufficiency. Mr. Milne reported that he was preparing a paper on behalf of the Blood Products Sub-Committee for presentation at the December meeting of the Executive Committee. Afr

83.134 CASE COMMITTEE:

The Co-ordinator reported that the Case Committee had met earlier in the day and wished to present the following recommendations to the Executive Committee:-

- (a) A grant of £40 to a young man with haemophilia in the North to assist with employment prospects (on social worker's recommendation).
 - (b) A grant of £40 to assist a family who were in general financial difficulties. This was made on the recommendation of a social worker involved with the family on account of a 13 year old haemophilic child.
 - (c) Agreement in principle to meet 50% of telephone installation costs for a young haemophilic in the North West. This was also on a social worker's recommendation. Afr
 - (d) Subject to the agreement of the local Group, a grant of £40 to assist a family who had approached the Society directly.
- That these recommendations be approved was proposed by Mr. Knight, seconded by Mr. Milne, and agreed unanimously.

83.135 GRANTS COMMITTEE:

The Co-ordinator reported that the Grants Committee had met earlier in the day and now made the following recommendations to the Executive Committee for reference to the next Council meeting:

- (a) That a grant of £2,480 be made to Dr. Tuddenham at the Royal Free Hospital to enable him to continue his work on von Willebrand's variants - work already supported in part by the Society.
 - (b) That no grant be made to Dr. Tuddenham in respect of a renewed application for payment of a revised amount of £5,000 (originally £17,623) in respect of work on prenatal diagnosis of haemophilia using DNA techniques.
 - (c) That North Wales Group be allowed to expend £900 (Approx.) on basic equipment at Ysbyty Glan Clwyd Hospital. The Group have the money which will be passed to the Society in the usual way.
- That these recommendations be approved was proposed by Mrs. Holliday, seconded by Mr. Johnstone, and agreed unanimously.

It was noted that there would be four applications for consideration at the December meeting of Council.

The Co-ordinator reported that further to the refusal of Dr. Craske's application for a computer in relation to his AIDS research programme, approaches had been made to the office of the Chief Scientific Officer (DHSS) and it now appeared likely that a grant would be made by the Department.

83.136 HONORARY SECRETARY'S REPORT:

Mr. Prothero reported that, in company with the Co-ordinator, he had visited the Scottish Group on the occasion of the Society's Annual Draw and Northern Ireland for their Annual General Meeting. He also reported that along with Mr. Abrahams he had attended the Haemophilia Centre Directors' Annual Meeting in Oxford. A detailed report would be circulated at a later date. One topic which Mr. Prothero felt should be discussed again by the Executive committee was that of the criteria for the designation of Haemophilia Centres. It was reported that the development of Elstree was on schedule.

83.137 HONORARY TREASURER'S REPORT:

		£.	p.
BALANCES:	Current Account	4,281.00	
	Ordinary Deposit Account	9,795.00	
	Fixed Deposit Account	90,000.00	
	Research Fund to date:	246,507.00	

Notable donations from 13 October 1983:

Sheffield Group £1,250 (£1,000 Research £250 General); Colchester Group £350 Research; Oxford Group £500 Research; N.E. Group £600 (£500 Research £100 General); N.W. Group £800 (£500 Research £300 General); London Marathon £2,916.83 Research; South Essex £1,000 (£800 Research £200 General); BHG Insurance Brokers £239.30 Research; In memory of **GRO-D** of Bovey Tracey £162 Research; Mr. **GRO-D** £84 General - sponsorship in local marathon; Mr. **GRO-D** £100 Research; South Wales Group £500 Research; Redundancy Payments Office £142.68 General; Northern Ireland Group £3,000 (£2,500 Research £500 General); **GRO-D** £100 General.

83.138 GROUPS: - Major agenda item left to the end of meeting.

83.139 WORLD FEDERATION OF HEMOPHILIA:

The Co-ordinator reported that WFH plans for the XVI Congress in Rio in 1984 were progressing and that discounts for non-haemophilic representations increased after 1 February 1984. Mr. Prothero reported that the cost per delegate started at £590 including accommodation. The Chairman reported that Bournemouth Corporation were most anxious to host a future Congress and had offered to ensure the Co-ordinator's expenses in order that a bid be made with a view to the UK hosting the Congress in 1988 or 1990. The Co-ordinator pointed out that it may be possible to link this with the I.H.T.C. meeting in either of those years. That advantage be taken of this possibility and that the Co-ordinator attend was proposed by Mrs. Britten, seconded by Mr. Abrahams. This was agreed with one abstention.

The Executive Committee went on to discuss Society representation in Rio. It was noted that the Chairman, in his role as Chairman of WFH, would be paid for by the World Federation. There was also a possibility of pharmaceutical company funding being available. It was agreed that at present it would not be possible to sponsor more than two delegates in addition to the Chairman and the Co-ordinator, although it may be possible to increase the number if pharmaceutical company funding were to become available. The Co-ordinator and the Secretary were asked to explore the possibility of funds being donated by the companies for this purpose.

83.140 CO-ORDINATOR'S REPORT

- (a) North Wales Group had contacted the Co-ordinator in relation to their caravan. This had not proved its need over the last summer and it also required a considerable amount of work done on it. The local Committee had reservations about continuing financial support (rates, site rent, etc.) for a caravan not being fully utilised. After detailed discussions with Mrs. Holliday it was proposed by Mr. Milne, seconded by Mrs. Britten, that, in view of the fact that this caravan was not serving a useful purpose, it should be sold forthwith. This was agreed, Mrs. Holliday not exercising her vote.
- (b) 1984 A.G.M. The Co-ordinator invited members of the Executive Committee to give careful consideration to the venue and topic for the 1984 A.G.M. This item will appear on the December agenda.
- (c) December Council Meeting: The Co-ordinator sought the guidance of the Executive Committee on the format of the a.m. session at the December Council meeting. Members are to let the Co-ordinator have suggestions at an early date.

83.141 ANY OTHER BUSINESS: There were no items of other business.

83.138 GROUPS:

This subject had been introduced to the agenda since it was generally felt that many Groups were facing problems in continuing in view of numerous changes which had taken place over the years in haemophilia treatment and care. A wide-ranging discussion took place following consideration of a paper presented by Mr. Prothero which outlined the 'pros' and 'cons' of the present situation. At the end of those discussions the Executive Committee were left to consider the following points:-

- (a) Should the status quo be maintained?
- (b) The possibility of voluntary, area, linkages of Groups.
- (c) Whether Groups should be re-structured on a regional basis.
- (d) It was agreed that the development of new Groups should be retained under strict control.
- (e) What were Group priorities now in view of developments in recent years?
- (f) Did the Society now require a different structure.
- (g) Was there a need for a deformalising of some Groups - e.g. The appointment of "area representatives" rather than formal Groups. This applied, perhaps, where Group committees were the only active persons working in a given area.

It was agreed that these matters should be considered further, both by the Executive Committee and local Groups for discussion on a future occasion.

The Honorary Treasurer and the Co-ordinator were asked to prepare financial returns (net and gross) in respect of Groups for presentation to the next meeting of the Executive Committee if possible.

83.142 DATE & PLACE OF NEXT MEETING: N.B. **Tuesday** 6 December 1983 at the Charles Bernard Hotel, 5 Frognal, NW3.
(Mrs. Holliday presents her apologies)

Asr.

GRO-C

6 December 1983.