

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 14 July 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,
Mrs. **GRO-A** Dr. L. Kuttner, K. Milne, Mrs. **GRO-A**
Mrs. **GRO-A**, Mr. **GRO-A**
In attendance: D.G. Watters

AGENDA

- 83.82 Apologies for absence
- 83.83 Minutes of the meeting held on 14 June 1983
- 83.84 Matters arising
- 83.85 Distribution of Council Meetings
- 83.86 Publicity
- 83.87 Case Committee
- 83.88 Research Grants
- 83.89 Honorary Secretary's Report
- 83.90 Honorary Treasurer's Report
- 83.91 Groups
- 83.92 World Federation of Hemophilia
- 83.93 Co-ordinator's Report
- 83.94 Any other business
- 83.95 Date of next meeting

83.82 APOLOGIES FOR ABSENCE: H.N. Abrahams, C. Knight, P. Wetherell

83.83 MINUTES OF THE MEETING held on 14 June 1983.
The Co-ordinator asked that the minute 83.70 be identified as a personal
paper from Mr **GRO-A** rather than Scottish Group.
The word 'problemated' was omitted from minute 83.72(d).
Thereafter the minutes were unanimously approved as an accurate record
of proceedings.

83.84 MATTERS ARISING

(a) Home Treatment: The members of the Executive Committee had received
copies of a letter from Professor Bloom dated 23 May 1983 and this
was discussed in detail. It was agreed that a letter of thanks be
sent to Professor Bloom explaining that the Society did indeed have
a growing appreciation of the distinction between Haemophilia Centres
and places where treatment may be available. Reservations previously
expressed by the Executive Committee would not necessarily apply any
longer and the Executive Committee hope to have an opportunity to peruse
the draft proposals which will be submitted to the next meeting of the
Centre Directors.

(b) A.I.D.S. The Chairman introduced this subject and commented upon the WFH Medical Board report presented at Stockholm by Dr. Shelby Dietrich. This report, prepared by leading haematologists from around the world carried the same essential message as that sent to our members in early May of this year. Southern Group had presented the following (unanimous) resolution for discussion:

"That the Society alerts the Minister to the fact that the German Government has banned American imports of blood products and the UK should do the same. The Southern Group is most concerned that we are still using factor VIII imported from America."

The following comments were made:-

1. The German government have **NOT** banned the import of American blood products.
2. There is no other country, despite press reports, in a position to supply sufficient blood products to meet current UK needs which can guarantee those products to be risk free.

The Executive Committee were unanimous in their view that the position in the UK remains as it did on 4 May when the Chairman wrote to all Society members along with a statement from Professor Bloom. It was agreed that the Co-ordinator should write to Professor Bloom giving him an opportunity to write again amending any statements in that letter. In the meantime a meeting with the Minister's Parliamentary Secretary - Lord Glenarthur - would be held on Thursday 8 September. The Chairman and Mr. Prothero would attend and Mr. Milne would provide briefing papers.

Since the Southern Group resolution was not, on information available, based on fact it was felt that no action could be taken on it.

It was agreed that the a.m. session at the next Council meeting would be devoted to AIDS. The Chairman to invite Professor Bloom to address the session.

(c) Staffing of 16 Trinity Street The Co-ordinator reported that following the last meeting four candidates for the full-time post of secretarial assistant had been interviewed by Mrs. **GRO-A** Mr. Abrahams and himself. Miss Irene Hawkins had been appointed and she commenced on Monday 11 July. It was also reported that the Redundancy Payments Office had recognised Mrs. Freeman's redundancy and in consequence a claim would be filed for 41% of her settlement of £417.60 (i.e. £171.22).

(d) Sub-Committee Structure: The Sub-Committee structure was agreed as follows:

<u>Research Grants:</u>	Rev. A.J. Tanner, Mr. D. Rosenblatt, Mr. J. Prothero Mr. H. Abrahams
<u>Case Committee:</u>	Mr. D. Rosenblatt, Mr. J. Prothero, Dr. L. Kuttner
<u>Administration:</u>	Mr. H. Abrahams, Mr. D. Rosenblatt
<u>Overseas:</u>	Mrs. GRO-A Mr. K. Milne, Mr. C. Knight

Seminar: Mr. C. Knight, Mr. J. Prothero, Mrs. **GRO-A**

Bulletin/

Publications: Mr. C. Knight, Mr. J. Prothero, Mr. Milne,
ex-officio the Revd. A.J. Tanner

It was stressed that newer members of the Executive Committee should feel free to intimate their desire to sit on Sub-Committees as they felt interested.

- (e) Lease 16 Trinity Street: It was noted that the agents had not yet been in touch regarding the renewal of the present lease held on the Society's offices. The Co-ordinator was asked to follow this up in conjunction with the Administration Sub-Committee.
- (f) **GRO-D**'s letter: Copies had been circulated and it was agreed that a valuation be obtained but if the value was not substantial, then it should be retained on file.
- (g) Meeting with WHY delegates and Mr. George Tharakan: The Co-ordinator reported that very happy and informal meetings had been held at 16 Trinity Street with the above. Mr. Prothero and Mr. Milne attended the WHY event while Mr. Milne attended the meeting with Mr. **GRO-D** along with Mr. **GRO-A** from Bristol Group and Mr. **GRO-A** from Sheffield Group. Mr. Milne expressed congratulations to the Co-ordinator for organising both events.
- (h) Christmas Cards: The Co-ordinator reported that an order had been placed for 30,000 Christmas cards which Groups would purchase and sell to members. The scheme would be advertised through The Bulletin.

83.85 DISTRIBUTION OF COUNCIL MEETINGS: The question of the unequal distribution of Council meetings had been raised at the June meeting. After detailed consideration it was agreed (with one abstention) that it be proposed to the Council that in future meetings be held early March, AGM & Council in May/June, September and November.

83.86 PUBLICITY: Mr. Knight had been unexpectedly prevented from attending the meeting at the last moment and in consequence this matter was further deferred.

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

- (a) A grant of up to 50% of telephone installation costs for a member in Yorkshire conditional upon the social worker obtaining the balance from other sources.
- (b) A grant of £70 to enable a member to go on one weeks holiday with his family on the recommendation of his Centre Director.
- (c) A grant of £20 for clothing to enable a young member to take part in the North Wales Adventure Holiday.
- (d) A grant of £60 to assist a member in Wales with general financial problems arising from a complicated Benefit's situation - this upon Social Worker's recommendation.

- (e) A grant of £20 to cover travel costs to enable a young member to have a holiday.
- (f) A grant of 50% of telephone installation costs for a member conditional upon the balance being obtained from other sources.
- (g) To increase a grant of £50 agreed at the last meeting in respect of removal costs to £64.43.

That the above recommendations be approved was proposed by Mr. Milne, seconded by Mrs. GRO-A and agreed unanimously.

83.88 RESEARCH GRANTS: No new major applications have been received but the Co-ordinator tabled two requests from Groups, as follows:

- (a) Northern Ireland Group sought authority to spend up to £150 for patient comforts at the Royal Victoria Hospital, Belfast. This was agreed unanimously.
- (b) Tayside Group had written requesting authority to assist Dr. Tudhope with expenses he will incur in connection with his visit to the UK Centre Directors' Meeting in October. After discussion it was proposed by Mr. Prothero, seconded by Mrs. GRO-A that this expenditure be disallowed. This was agreed unanimously.

83.89 HONORARY SECRETARY'S REPORT: Mr. Prothero reported that he had visited York House to meet the Duchess of Kent's staff. He reported the total satisfaction of the Patron with the present running of the Society. The Chairman thanked Mr. Prothero for undertaking this liaison with the Duchess of Kent's Private Secretary.

Mr. Prothero also raised the question of expenses of £20 incurred by Sister Fearnis in connection with her work for the WFH Home Treatment Committee. It was proposed by Mr. Rosenblatt, seconded by Dr. Kuttner that these expenses be met in full. This was agreed unanimously.

83.90 HONORARY TREASURER'S REPORT In the absence of Mr. Abrahams, the Co-ordinator read his report.

BALANCES:-	£.	p.
Current Account		285.45
Ordinary Deposit Account	11,030.97	
Fixed Deposit Account	90,000.00	
Research Fund to date:	233,433.44	

Notable donations:
 Mrs. GRO-D £222.76 Research; South Wales Group £1000.00 Research and £200 General; G.O.S. Group £180.29 Research; Metal Closures G.P. Trustees £50 General; Inland Revenue refund re Deeds of Covenant £2,033.44 General; Mr & Mrs GRO-D Sudbury £70 Research; In memory of GRO-D £54.18 Research.

The Co-ordinator also reported on behalf of the Honorary Treasurer that earlier in the year the Executive Committee agreed to purchase a quantity of ball-pens bearing the Society's name. The matter had been investigated by the Co-ordinator and subsequently an order was placed with L. Thompson (Advertising) Ltd. This was on a pro-forma basis (i.e. cash with order). This company had been used before and was a major company supplying the charity market as well as industry. Early in March we were advised that a meeting of creditors had been called for 18 March 1983 and subsequent

enquiries have revealed that there will be no possibility of any of the £1,200 paid being recovered by the Society or any of the other 10-12 charitable organisations who have lost equal sums of money and that no pens could now be supplied. This was noted by the Executive Committee.

It was reported that since Finance Act 1983 Deed of Covenant payments to Charity by higher rate tax payers now attract higher rate tax relief up to £5,000 of payments - previously £3,000.

The Co-ordinator reported that North Wales Group sought formal approval to expand the funds held by the Group on account of their caravan and the North Wales Adventure Holiday. That this be approved was proposed by Mrs. GRO-A seconded by Mr. Milne. This was agreed unanimously. Mrs. GRO-A also raised the question of the Group caravan which was being under used. She was asked to liaise on this with the Co-ordinator who understood that another Group may be interested in a newer caravan.

- 83.91 GROUPS: The Co-ordinator reported that he had visited the Birmingham Group on 11 July and had given a talk on Mobility Allowance. Mr. Prothero reported that he had attended the AGM of the North Wales Group and had spoken about WFH. Mrs. GRO-A expressed her thanks to Mr. Prothero.
- The 1984 Seminar will be held on the weekend of March ~~11-13~~, again at ~~9-11~~ *AJT.*
The Durlston Court Hotel in Bournemouth.
- The Co-ordinator had been in touch with Northern Group.

83.92 WORLD FEDERATION OF HEMOPHILIA:

- (a) The Chairman reported on the XV WFH Congress held in Stockholm from June 27-July 1. There had been a record number of UK people there, some 64 including all hospital and pharmaceutical company delegates. A discussion was held on the strengths and weaknesses of the Congress.
- (b) Mrs. GRO-A read a letter from Nathan Smith, President of The National Hemophilia Foundation USA, congratulating the Society for its initiative in assisting the development of work for people with haemophilia in India. In this connection the Chairman reported that Professor Manucci had asked him to attend the conference in India during November to help forward the establishment of a National Haemophilia Society in India and our own links with it. It was felt, in particular, that the Chairman's attendance, in his role of Chairman of WFH, could help to bridge the cultural gap between doctors and patients in India. After discussion it was agreed by 6 votes with 1 abstention and 1 opposing vote, that, provided funds were available from sources other than the Society, the Chairman should attend. The Co-ordinator was asked to explore the possibility of funding in conjunction with Mr. Prothero.
- (c) WFH 'bonus': The Co-ordinator drew the attention of the Executive Committee to the sum of US dollars 623 held as a bonus by WFH. After discussion it was agreed that this sum should be deducted from the 1984 assessment and that the Co-ordinator should write to Mr. Mjelde, Treasurer of WFH, in those terms.

83.93 CO-ORDINATOR'S REPORT: The Co-ordinator reported that he would be on holiday from 22 August to 2 September inclusive.

83.94 DATE & PLACE OF NEXT MEETING: Thursday 11 August 1983 at the White Hall Hotel at 6 p.m. for 6.30 p.m.

Please note: Autumn Council Meeting date now 8 OCTOBER 1983.

GRO-C: Alan Tanner

83.

11/11/83