



THE HAEMOPHILIA SOCIETY

P.O. BOX 9 · 16 TRINITY STREET · LONDON, SE1 IDE

Telephone : 01-407 1010

MINUTES OF THE MEETING OF THE EXECUTIVE COMMITTEE OF THE HAEMOPHILIA SOCIETY held on Thursday 14 June 1984 at 6.30 p.m. in the Senator Room, the Kennedy Hotel, Cardington Street, London, NW1.

Those present: The Revd.A J Tanner, Mr D Rosenblatt, Mr J Prothero, Mr H Abrahams, Mrs M I Britten, Mrs C Holliday, Dr. L Kuttner, Mr K Milne, Mr D Watters.

AGENDA

- 84.55 Apologies for absence.
- 84.56 Minutes of the meeting held on 10 May 1984
- 84.57 Matters arising.
- 84.58 Blood Products Sub-Committee.
- 84.59 Case Committee.
- 84.60 Research Grants Committee.
- 84.61 Honorary Treasurer's Report.
- 84.62 World Federation of Hemophilia.
- 84.63 Co-ordinator's Report.
- 84.64 Any other business.
- 84.65 Date and place of next meeting.

84.55 APOLOGIES FOR ABSENCE: were received from Mrs GRO-A, Mr Johnstone, Mr Knight and Mr Wetherell.

84.56 MINUTES of the meeting held on 10 May 1984 were approved unanimously after minor textual amendments.

84.57 MATTERS ARISING

- (a) R.G.Macfarlane Award: The Chairman reported that he had received a warm and ~~grateful~~ ^{grateful} letter from Dr Tuddenham, in which he ~~accepted~~ ^{accepting} the 1984 R G Macfarlane Award.
- (b) Appointment of Personal Assistant to the Co-ordinator: The Co-ordinator reported that the person who had been offered the post had requested entry to the Society's pension scheme after a three month probationary period. After discussion it was unanimously agreed that this would not be possible. Subject to any decision by that person to whom the job had been offered it was further resolved to offer the appointment to Miss Irene Hawkins. It was further agreed that with effect from 1st July 1984, Miss Hawkins salary be increased by 3 points on the applicable salary scale subject to her acceptance of the post.

MSJ

- (c) Future Development of Groups: The Co-ordinator tabled a paper for further consideration. It was agreed that this subject be discussed during July and August and presented to the September meeting of the Council.
- (d) A.I.D.S.: There was nothing new to report apart from the circulation of HAEMOFACT 3.

84.58

BLOOD PRODUCTS SUB-COMMITTEE: Mr Milne and Mrs Britten reported on their visit to the Transfusion Centre in Birmingham. Dr. Ala had been most helpful and a number of new questions had been raised by the visit. These points required further consideration and would be embodied in a paper for presentation to the next meeting.

The Executive Committee also received Mr Milne's paper requested in Minute 84.48(iii) and approved this after minor textual amendments. This will be included in a future Bulletin or HAEMOFACT.

The Blood Products Committee were also asked to explore, with the Department of Health, questions surrounding blood collection procedures around the country.

84.59

CASE COMMITTEE:

- (i) Mr Rosenblatt 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 £150.00 to a member to enable him to defray an outstanding debt on the purchase of a fridge/freezer bought originally for the storage of porcine factor VIII.
 - (b) A grant of up to £105.00 to enable a seven year old severe haemophiliac to attend the North Wales Adventure Holiday.
 - (c) No grant to the mother of a child with haemophilia, the father being the child's guardian and the mother living apart.
 - (d) A grant representing 50% of telephone installation costs for a member in the North West.
 - (e) A grant of £31.00 to enable a 19 year old member to join a Sports Centre and hopefully, reduce his social isolation.
 - (f) A grant of £40.00 to assist a member with removal costs - the grant only being required if Supplementary Benefit could not pay.
- That those proposals be adopted was proposed by Mr Rosenblatt, seconded by Mr Milne, and approved unanimously.

- (ii) Grants during post-operative periods: Having carefully considered the proposition - namely, that a small weekly allowance be available to people while they were, for example, incapacitated after an operation. It was decided unanimously not to pursue the matter. The Executive Committee agreed that lump sum grants were more likely to be of practical assistance to people facing hardship. It was pointed out that in 1983 only 3 applications had been refused and that it was open to anyone to make application. AJT
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84.60

RESEARCH GRANTS COMMITTEE

- (a) Dr Ian Peake, Cardiff: Having considered the replies from the Medical Advisory Panel the Grants Committee were not prepared to recommend a grant in response to this application. It was considered that the work was of a nation-wide nature and as such central government was a more appropriate source to be ~~encouraged~~ ^{approached} for funding. This was agreed unanimously. AJT
- (b) Mr [GRO-A] Dr Savidge, St Thomas', London: The Grants Committee recommended that no grant be made in response to an application for £5,470.50 to supply various pieces of orthopaedic equipment. It was felt that this was of a standard nature and that there was no unusual feature of research involved. This was agreed unanimously.
- (c) Restructuring of the Research Grants Committee: The Executive Committee had received the paper prepared by the Co-ordinator in consultation with the Chairman. The Executive Committee noted the conclusions of the paper:-

- (a) To implement ALL Professor Bloom's suggestions would be to use a sledge hammer to crack the proverbial nut.
- (b) Work must be done quickly and soon on the matter of internal budgets.
- (c) The matter of 'special cases' where Groups raise money for projects would not be affected in any way by this revision: they would still be required to make application for any proposed expenditure PRIOR to raising their first penny!

and ~~having been~~ ^{having been} proposed by Mrs Britten, seconded by Mrs Holliday, the Executive Committee adopted the ~~following~~ ^{following} AJT
~~conditions~~ ^{conditions} follows:-

- (1) OFFICERS of the Society continue to sift applications and decide which applications should be referred to the Medical Advisory Panel.
- (2) The Medical Advisory Panel would constitute a formal Committee who would study applications (twelve copies - or whatever number - having been provided by the applicant)

and 'score' them in accordance with a form similar to that attached.

- (3) The above Committee would not be required to meet.
- (4) The Committee's recommendations would be subject to final confirmation by the Executive Committee (and Council) of the Society.
- (5) Individual applications for welfare grants would continue to be considered by the Case Committee, as at present.

The paper will be circulated in advance of the September meeting of the Council for adoption.

84.61

HONORARY TREASURER'S REPORT

Mr Abrahams reported balances as follows:-

Ordinary Deposit Account	£15,068.76
Special Deposit Account	£70,000
Current Account	£2,786.13

On behalf of the Committee Mr Milne expressed sincere thanks to Mr Abrahams for all the work he had done for the Society during his time as Treasurer, and while understanding only too well his reasons for standing down, regretted that decision. Those sentiments were echoed by all present.

84.62

WORLD FEDERATION OF HEMOPHILIA: It was noted that Ken Milne had prepared the UK presentation and sent it to Montreal.

84.63

CO-ORDINATOR'S REPORT

- (a) Annual Draw: The Co-ordinator reported that the following major prizes had been donated - a holiday for two in Tenerife, a week for two at the Durlston Court Hotel, Bournemouth; an electric typewriter; return trip to the continent with Townsend Thoresen. It was agreed that the Society provide £100.00 for second prize.
- (b) It was noted with regret that there would be NO 1984 Christmas cards.
- (c) The Co-ordinator reported that the new LIVING WITH HAEMOPHILIA was due out on 1st July and that 5 advance publication copies would be available at the AGM.
- (d) The Co-ordinator drew the attention of the Executive Committee to the fact that he had undertaken a review of all cases involving Mobility and Attendance Allowance. To date some 94 awards had been made - representing about £94,000 p.a income to the membership. He had no doubt that the figure was substantially greater but could not prove it from available

(d) Continued

Analysis would continue and a full report would be available in the future.

84.64 ANY OTHER BUSINESS: There was no other business.

84.65 DATE AND PLACE OF NEXT MEETING: Thursday 12th July at 6.00pm. Venue to be announced.

N.B. Venue - Ludlow Room, Great Western Hotel, Paddington Station, W.2.

Approved as an accurate record of proceedings on 12th July 1984

Signed _____

GRO-C

CHAIRMAN