

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 12 May 1983 at 6.30 p.m. at the White Hall Hotel, Montague
Street, London WC1.

Those present: The Revd A.J. Tanner; D. Rosenblatt; H.N. Abrahams; Mrs. M.I. Britten; Dr. L. Kuttner; C. Knight; K. Milne; Mrs. D. Lewis; Mrs. C. Holliday; P. Wetherell; W. Johnstone
In attendance: D.G. Watters

AGENDA

- 83.52 Apologies for absence
- 83.53 Minutes of the meeting held on 12 April 1983
- 83.54 Matters arising
- 83.55 A.G.M. Report back
- 83.56 Case Committee
- 83.57 Research Grants Committee
- 83.58 Honorary Secretary's Report
- 83.59 Honorary Treasurer's Report
- 83.60 Groups
- 83.61 Induction day for new Executive Committee members
- 83.62 World Federation of Hemophilia
- 83.63 Co-ordinator's Report
- 83.64 Any other business
- 83.65 Date & Place of next meeting

The Chairman opened the meeting by welcoming everyone to the first meeting of the newly elected Executive Committee. He extended a special welcome to the new members - Mrs. Holliday, Mrs. Lewis and Mr. Wetherell.

83.52 APOLOGIES FOR ABSENCE were received from Mr. Prothero.

83.53 MINUTES of the meeting held on 12 April 1983, which had been circulated in advance were unanimously approved as an accurate record of proceedings.

83.54 MATTERS ARISING:

- (a) Oxford Lottery: Mr. Rosenblatt reported that there had been no further communication received regarding this matter.
- (b) National Lottery: Mr. Rosenblatt reported that there had been agreement at the Council meeting on 23 April to proceed with a pilot scheme. However, it was felt that there had been a general lack of enthusiasm and that, as a good deal of work would be required from any Group volunteering to be involved in the pilot scheme, a much greater degree of interest would be required for the trial to be launched.

83.54 MATTERS ARISING (b) continued

Mr. Rosenblatt would draft a letter to be circulated to Groups in which they would be advised of their involvement in the scheme and the general level of expectation of them if they were to take part.

- (c) Incorporation: It was reported that the Extraordinary General Meeting on 23 April had approved the amendment to the existing Rules and Regulations and that the Draft Memorandum and Articles of Association had also received approval. The meeting had also agreed that, subject to Incorporation, the present Society be wound up and its assets transferred, having settled all debts and liabilities, to the new Company. The Solicitors now required to know the names of the Subscribers and First Directors. After careful discussion it was decided that the members of the Executive Committee should comprise both the Subscribers and the First Directors. This was agreed by 9 votes to 1.

83.55 AGM REPORT BACK: The Chairman remarked upon the satisfactory nature of the day and the arrangements and the members of the Executive Committee agreed that the format had been most successful.

The meeting proceeded to consider two particular topics arising from the AGM:-

- (a) Home Treatment: It was noted from Professor Bloom's talk that the Centre Directors had wound up their Home Treatment Committee since some 80% of those originally felt to be eligible were now benefiting from home therapy. The Executive Committee felt that the original parameters may have been too narrow and noted the 'patchy' nature of home treatment programmes, with the highest occurrence in major cities where the need could be less than in rural areas. The discussion also extended to follow-up clinics and the paucity of such facilities in certain areas was noted. It was agreed that the Co-ordinator should draft a letter for submission to Professor Bloom, outlining the Executive Committee's anxieties in this connection.

- (b) AIDS: The Chairman introduced the ^{Subject A} present AIDS scare in the UK and referred to the dossier of press cuttings which had been made available to all members of the Executive Committee. It was agreed that the Co-ordinator should take appropriate steps in connection with "The Mail on Sunday" and it was noted that one Centre Director had already lodged a formal complaint with the Press Council. The Chairman outlined his action in mailing his letter of 4 May 1983 to the entire membership of the Society and it was agreed unanimously that until there is evidence to prove otherwise the Society's policy would be to encourage members to continue with their present treatment programmes, subject to the advice of their Centre Directors, and that full support would be given to self sufficiency in blood products at the earliest possible date.

A meeting with the Minister (Mr. Finsberg) had been arranged for 20 May but the forthcoming General Election had led to this being abandoned until after the elections. However, when the meeting is held the main agenda items will be as follows:-

- (i) An assurance from HMG that self sufficiency in blood products within two years will remain a priority, with every effort being made to reduce this period.

83.55 AGM REPORT BACK continued

- (ii) That there will be no attempt to suspend the importation of US commercial products without definite evidence that this would be necessary.
- (iii) That the government give adequate support to research into AIDS in the UK.

The Executive Committee approved letters sent to Clive Jenkins (ASTMS) and Michael Foot suggesting that they were wrong in seeking to ban all blood product imports forthwith.

It was emphasised that all Groups should continue to seek guidance from their Centre Directors in relation to treatment programmes.

83.56 CASE COMMITTEE: The Co-ordinator reported on the meeting of the Case Committee which had met earlier in the day and presented the following recommendations to the Executive Committee:-

- (a) That a grant be made available to enable up to three boys to take part in the North Wales Adventure Holiday. This was at the request of a social worker and on the advice of the Centre director.
- (b) A grant of £50 to assist with the removal expenses of a family being rehoused on medical grounds.
- (c) There were three requests for assistance with funeral expenses. While the Case Committee were happy to recommend payment of £100 in each case, they wished to receive the guidance of the Executive Committee.

Following discussion it was agreed unanimously that the balance due in each case be met in full by the society.

- (d) It was noted that the provisional approval given at 83.29(b) was not open for confirmation, the necessary support having been obtained.
- (e) A grant of £50 to assist a family obtain home therapy.

That the recommendations be approved was proposed by Mr. Knight, seconded by Mr. Milne and agreed unanimously.

83.57 RESEARCH GRANTS: The Chairman introduced the report of the Research Grants Committee by remarking generally on acquired immune deficiency syndrome and grant applications relating to this. As anticipated a number of applications had been received and the indications were that further applications ^{might} be forthcoming. It was generally felt that a policy would be required to enable the applications to be administered fairly. It was agreed that following the consideration of the three applications tabled at this meeting, no further grants for AIDS-related projects would be considered until the Medical Advisory Panel had been consulted. This was proposed by Mr. Knight, seconded by Mrs. Lewis.

The Executive Committee proceeded to consider the following applications on which advice had been sought from the Medical Advisory Panel.

- (a) Dr. Machin, Middlesex Hospital: This application had been referred back by the Council for the attention of the Medical Advisory Panel. It was agreed following discussion that this project came low in present priorities and as such should not succeed. This will be recommended to the September meeting of the Council.

83.57 RESEARCH GRANTS continued

- (b) Dr. Rizza/Mr. Winship, Oxford: This matter had also been referred back from the Council meeting for further consideration by the Medical Advisory Panel. After detailed discussion it was agreed unanimously that no grant should be made. This will be reported to the September meeting of the Council.
- (c) Dr. Savidge, St. Thomas', London: This AIDS-related application had been outlined to the Council meeting and subsequently referred to the Medical Advisory Panel. While the application sought £8,235 for an MLSO and £3,000 for consumables, it was agreed that, subject to the agreement of Groups who will be written to urgently, that a grant of £8,000 be made available to enable the MLSO to be employed as soon as possible and in advance of the next meeting of the Council.
- (d) Dr. Kernoff, Royal Free Hospital, London: An urgent application had been submitted to examine the effects of blood products on the immune system of patients with haemophilia. This would involve a computer analysis of some 15,000 treatment records over the years 1980 and 1981. A total grant of £4,830 was sought to cover the employment costs of a part-time clerical officer who would prepare and validate records, enter them on the computer and carry out a preliminary analysis. The Executive committee agreed unanimously to use its emergency powers to grant £2,000 forthwith to enable the work to begin. The remainder will be brought to the September meeting of the Council for approval.
- (e) Dr. Forbes, Glasgow: An application relating to AIDS had been received in the sum of £2,000 which will fund materials, the majority of the funding coming from other sources, the staff seeking no extra payment for their work. The project involves a long-term longitudinal study of cell function, complement function and clinical evaluation. It was again agreed to use the emergency powers bestowed on the Executive Committee and to agree the grant forthwith, ratification by the Council being sought in September.
- (f) Birmingham Group: Sought authority to spend up to £500 of their own funds on an additional fridge/freezer for their new treatment room. This was approved unanimously.
- (g) South Wales Group: Sought authority to purchase a new wheelchair for use at their Cardiff Centre. This was approved unanimously.

83.58 HONORARY SECRETARY'S REPORT: There was no report since Mr. Prothero was on holiday. The Chairman drew everyone's attention to the Sub-Committee structure of the Executive Committee and invited those with special interests to report to him.

83.59 HONORARY TREASURER'S REPORT:

BALANCES:-	£.
Current Account	1,227
Ordinary Deposit Account	14,688
Fixed Deposit Account	100,000
Research Fund to date:	229,075

- 83.59 HONORARY TREASURER'S REPORT continued
Notable donations: Estate of GRO-D £200 Research; Birmingham Group £400 Research £100 General; Northern Group £500 General; S.Wales Group £500 Research; Sheffield Group £300 Overseas; Northern Ireland £1,000 Research £500 General; The Lacon Arms Public House, Great Yarmouth £350 Research; Mercantile Credit Co. £250 General; B.P. Group of Companies £150 General; The Podde Trust £100 General; Wilkinson Sword £500 General; P.J. Gibbs £60 General.
Mr. Abrahams also mentioned that he had heard from Dr. Mibashan regarding NHS funding for pre-natal diagnosis. It was noted that should such funding become available our present grant would stop.
- 83.60 GROUPS: The Co-ordinator reported that he had attended the AGM of the Ladywood Group (now The Birmingham Group) which had been very well attended and addressed by Dr. Peter Jones.
Leicester Group reported difficulties with their ambulance service and evening/weekend cover for people with haemophilia. The Co-ordinator was asked to liaise with the relevant authorities.
Scottish Group had submitted a paper on Group/Executive Committee relationships and this will appear as an Agenda item at the next meeting.
Great Ormond Street Group it was noted that GOS Group had closed on account of insufficient support.
Notts & Derby: The Executive Committee noted that this Group, suspended earlier in the year, was due for further consideration at an early date.
- 83.61 INDUCTION of new Executive Members: It was agreed that an afternoon induction session would be held for new members on the day of an Executive Committee meeting.
- 83.62 WORLD FEDERATION OF HEMOPHILIA:
(a) Assessments - it was noted that Mr. Rosenblatt would represent the Society view of WFH Assessments at the forthcoming Congress.
(b) The report of the International Haemophilia Training Centres was received.
(c) The Co-ordinator and Mrs. Britten reported on plans for GRO-D's visit to Stockholm.
- 83.63 CO-ORDINATOR'S REPORT:
(a) A detailed report has been received from the Irish Haemophilia Society following their visit to the UK earlier in the year.
(b) It was agreed that the Editor of The Bulletin and the Co-ordinator explore the possibilities of selling Orkney Islands sweaters through The Bulletin, thereby making a profit for the Society.
(c) Staffing at 16 Trinity Street The Executive Committee discussed GRO-D's situation and the matter was referred to the Administrative Sub-Committee to take advice and report accordingly. It was decided that GRO-D's full-time replacement would be recruited through press/Job Centre advertising.
- 83.64 ANY OTHER BUSINESS: There was no other business.
- 83.65 DATE AND PLACE OF NEXT MEETING: The Chairman announced that he would be in hospital for a few days from 22 May, and accordingly the date of the next meeting was changed to TUESDAY 14 June 1983 at the White Hall Hotel.

GRO-C

14 June 83.