



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 10 January 1985 held at the Kennedy Hotel, London, NW1.

Those present:

Revd. A J Tanner, Mr K Milne, Mrs M I Britten,
Mr K Colthorpe, Mrs C Holliday, Mr C Knight,
Dr. L Kuttner, Mrs D Lewis, Mr D Watters.

AGENDA

- 85.01 Apologies for absence
- 85.02 Minutes of the meeting held on 6 December 1984
- 85.03 Matters arising
- 85.04 AIDS
- 85.05 Blood Products Sub-Committee
- 85.06 Finance Sub-Committee
- 85.07 Case Committee
- 85.08 Treasurer's Report
- 85.09 World Federation of Hemophilia
- 85.10 Local Groups/Society Representatives
- 85.11 Co-ordinator's Report
- 85.12 Any other business
- 85.13 Date and place of next meeting

85.01 APOLOGIES FOR ABSENCE were received from Mr Rosenblatt, Mr Prothero,
Mr Abrahams and Mr Wetherell

85.02 MINUTES of the meeting held on 6 December 1984, which had been
circulated in advance, were approved unanimously, having been
proposed by Mr Knight and seconded by Mrs Lewis (after a number
of minor textual amendments had been made).

85.03 MATTERS ARISING:

(a) St Thomas' Hospital: No specific reply had yet been received
to the detailed letter sent to Lord Glenarthur on 3 December 1984.
It was hoped that the Supra-Regional Centre Directors would make
a concerted response to Health Notice 83/36 and that, as a result,
haemophilia could become a recognised Supra-Regional service.

(b) 1985 Residential Seminar : The Co-ordinator reported that all
the speakers and workshop leaders had been selected for the Seminar
and invitations had been sent to a number of Society members. Groups
had been asked to nominate their representatives by 1st February 1985.

(c) Restructuring of Executive Committee Meetings: Mr Knight had not been able to prepare his written report on this subject and it was agreed it should be deferred for a few months as it was important for the Executive Committee to continue with the present programme of meetings for the time being so that developments in AIDS might be monitored.

(d) Lord Mayor Treloar College Study Day: Dr.Kuttner reported that he had represented the Society at this most worthwhile study day.

85.04

AIDS: The Chairman and the Co-ordinator reported on the present situation. The Executive Committee were concerned that the introduction of heat-treated materials has been "patchy" and that at least one Supra-Region had not yet introduced heat-treated materials. There was wide disparity in the practise of individual Centres which made the situation very difficult for patients travelling within the United Kingdom.

Concern was also expressed that the re-inforced leaflet for donors was not yet available while many Transfusion Regions had exhausted their supplies of the old leaflet. Many regions still had no warning notices for "at risk" donor groups.

It was noted that Dr Peter Jones was preparing a new booklet on AIDS for donors, risk groups and recipients of blood and blood products.

It was further noted that the Special Interest Group for Social Workers was holding a meeting early in February to discuss counselling and support for people with AIDS, their families and hospital staff.

It was agreed that the Co-ordinator carry out the following tasks:-

(a) establish a meeting between representatives of the Executive Committee and the Medical Advisory Panel.

(b) write to Lord Glenarthur regarding the lack of progress in the production of the re-inforced AIDS leaflet.

(c) write to the Pasteur Institute in Paris regarding a short press-cutting produced at the meeting.

85.05

BLOOD PRODUCTS SUB-COMMITTEE: Mr Milne reported that representatives of the Blood Products Sub-Committee would meet with representatives of the pharmaceutical companies at the Kennedy Hotel on Saturday 26 January 1985.

85.06

FINANCE SUB-COMMITTEE: In the absence of Mr Rosenblatt, the Co -ordinator reported on the last meeting of the Finance Sub-Committee held on 10 December 1985. It was noted that Mr Rosenblatt would not continue to Chair this Sub-Committee which felt that it had, by and large, achieved its major objectives.

85.07

CASE COMMITTEE: Mr Milne reported on behalf of the Case Committee which had met earlier in the evening. As a result of their deliberations the following recommendations were made to the Executive Committee:-

(a) A grant of £100 to a member in North Wales to assist with expenses likely to be incurred in connection with surgery.

(b) A grant of £100 to a member in London to assist with exceptional hardship following desertion by her husband.

(c) A grant of £50 to assist with travel costs of a member in the South .

(d) A grant of £10 to assist with the clothing needs of a member (vWd) in the North.

(e) A grant of £40 to assist a member with 3 haemophilic boys with problems arising from general hardship in the North.

(f) A grant of £40 to a member in the North to assist with fares, etc, for physiotherapy .

(g) A grant of £10 to assist with fares for hospital visits to a member in the North.

(h) A grant of £25 to assist with removal costs of a member in the North East .

(i) A grant of £25 to assist a single parent member in general financial difficulties, living in the North East.

That these recommendations be approved was proposed by Mrs Lewis, seconded by Mr Knight and agreed unanimously.

After further discussion the Executive Committee noted, as a matter of general policy, that no application should be presented to the Case Committee without a Social Worker's recommendation, unless there were special reasons for doing so which should be explained to the Executive Committee.

85.08

TREASURER'S REPORT: (a) Current position The Co-ordinator reported the current financial situation as follows:-

Current Account	£14,000
Ordinary Deposit Account	£17,417
Special Deposit Account	£90,000

The following notable donations were reported:

Legacy (Cyril Metcalfe) £5,271.19, Legacy (Mrs Mary Geddes) £1,000, Norfolk & Norwich Group £200, The Moorgate Trust Fund £4,000, Sir Arthur Black Charities £150, L G Uridge Charitable Trust £200, Sheffield Group £600, DJ & BL Campbell £213, Barclays Bank PLC £100, Mrs G A Bacon £70, Bolton Business and Professional Womens Club £75, Mrs E Thresher £80, Hunting Group Management £50, South Wales Group £1,000, Mrs S Lee £164, Messrs Coutts & Co £150 (second donation), All Saints Church Tooting £235, London Metal Exchange Benevolent Fund £50, The Marsh Christian Trust Fund £100, Courtaulds Apparel Ltd £100, Alpha Therapeutic £500.

TOTAL DONATIONS PROMISED TOWARDS THE ANNUAL SEMINAR £3,000 plus an unspecified amount from Immuno.

(b) Annual salary reviews: The chairman reported that in accordance with established practice Miss Hawkins' salary would be increased from point 12 to point 13 on the appropriate scale. Likewise the Co-ordinator's salary would be increased from point 37 to point 38.

Following private discussion between members of the Executive Committee (in the absence of the Co-ordinator) it was also agreed that in recognition of the rapidly expanding responsibilities carried by the Co-ordinator, his salary scale should be reviewed. This is to be finalised after more detailed discussion between the Chairman and the Treasurer.

- 85.09 WORLD FEDERATION OF HEMOPHILIA: There was nothing to report.
- 85.10 LOCAL GROUPS/SOCIETY REPRESENTATIVES: The Co-ordinator reported that the Colchester Group had elected a new Committee and were therefore back in business. He also reported on a contact he had with a group (mainly of mothers) in Portsmouth who were dissatisfied with treatment facilities there. He will attend their February meeting.
The Co-ordinator also reported that he would proceed to appoint Mr GRO-C (Sussex) and Mr GRO-D (Truro) as Society Representatives. This was agreed.
- 85.11 CO-ORDINATOR'S REPORT: The Co-ordinator was formally nominated as the Society's representative to the Greater London Association for the Disabled (GLAD).
- 85.12 ANY OTHER BUSINESS: There was no other business.
- 85.13 DATE AND PLACE OF THE NEXT MEETING: Thursday 7 February 1985 at the Kennedy Hotel, London, NW1 in the Senator Room at 6pm for 6.30pm.

Approved on GRO-C as an accurate record of proceedings.
Signed 7 February 1985 Chairman