



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 7 February 1985 at the Kennedy Hotel, London, NW1 2LP

Those present: Revd.A J Tanner, Mr D Rosenblatt, Mr K Milne, Mr J Prothero, Mr H Abrahams, Mr K Colthorpe, Mr C Knight, Dr. L Kuttner, Mrs D Lewis, Mr D Watters.

## AGENDA

- 85.14 Apologies for absence
- 85.15 Minutes of the meeting held on 10 January 1985
- 85.16 Matters arising
- 85.17 AIDS
- 85.18 Blood Products Sub-Committee
- 85.19 Case Committee
- 85.20 Treasurer's Report
- 85.21 Research Grant Applications
- 85.22 World Federation of Hemophilia
- 85.23 Local Groups/Society Representative
- 85.24 " 1985 Annual General Meeting
- 85.25 Co-ordinator's Report
- 85.26 Any other business
- 85.27 Date and place of next meeting

85.14 APOLOGIES FOR ABSENCE: were received from Mrs M I Britten, Mrs C Holliday and Mr P Wetherell.

85.15 MINUTES of the meeting held on 10 January 1985, which had been circulated in advance, were unanimously approved as an accurate record of proceedings at that meeting.

85.16 MATTERS ARISING:  
(a) St Thomas' Hospital: The Co-ordinator reported that Lord Glenarthur had referred the questions raised by the Society to the Chairman of the South <sup>West</sup> Thames <sup>Area</sup> Health Authority. A response was now awaited from that source.  
(b) 1985 Residential Seminar: The Co-ordinator reported that plans were well in hand and over 100 people would be attending.

85.17

AIDS: (i) The Co-ordinator introduced a discussion on AIDS under the following headings:-

(a) The apparent lack of direction from Reference Centres to Centres and Associate Centres

(b) The varied and unco-ordinated approaches by Centres to the present situation, stressing in particular the difficulties caused by (a) and (b) in dealing with enquires from members

(c) The lack of confidentiality from hospital staff with personal details about AIDS patients being apparently freely available

(d) The situation at HMP, Chelmsford, which suggested that the DHSS were not being as forthright as they ought to the Home Office  
After detailed discussion it was decided to raise matters (a) to (c) at the forthcoming meeting with the Medical Advisory Panel and it was hoped that the hysteria of (d) would resolve itself with behind-the-scenes assistance from the Society

(ii) AIDS AND THE BLOOD: Dr Peter Jones' new book was discussed and it was unanimously agreed that it be mailed, free of charge, to all Society members. The book will be publicly launched by the Society, with Dr Jones in attendance, on Tuesday 12 February.

(iii) Response to Lord Glenarthur: It was noted that, after the meeting with the Medical Advisory Panel, we would be in a position to respond to the reply from Lord Glenarthur, following our meeting with him in December

(iv) Support: Both Mr Knight and the Co-ordinator spoke of their feelings of isolation in handling the work arising from AIDS.

The Chairman will meet to discuss the situation with them early next week and in the meantime the Co-ordinator was given unanimous authority to seek a support-team to whom he could have access.

85.18

BLOOD PRODUCTS SUB-COMMITTEE: Mr Milne reported on the meeting between representatives of pharmaceutical companies and the Blood Products Sub-Committee. The meeting had been most useful in providing a constructive forum to discuss items of common interest. It was proposed to have a similar meeting later in the year to which Blood Products Laboratory personnel would be invited.

85.19

CASE COMMITTEE: Mr Prothero reported that the Case Committee had met earlier in the evening and wished to make the following recommendations to the Executive Committee:-

(a) A grant of £80 to a family to enable them to purchase a fridge for the storage of factor VIII for home treatment of their two haemophilic sons

(b) A grant of £20 to assist a member with items of household equipment following her move to a new address (son is a haemophiliac)

(c) A payment of up to 50% of the cost of telephone installation for a member on home therapy.

That these recommendations be adopted was proposed by Mr Prothero, seconded by Mr Colthorpe and agreed unanimously.

85.20

## TREASURER'S REPORT:

(a) The Current position: Mr Prothero reported the following bank balances:-

Current Account	£19,000
Ordinary Deposit Account	£17,417
Special Deposit Account	£90,000

The following notable donations were reported:-

In memory of [GRO-D] of Stockton £90, Robert Fleming and Company £500, In memory of Mrs [GRO-D] £100, Troon Breakers Club £110, Miles Laboratories £1000, United Grand Lodge of England £500, [GRO-D] £70, [GRO-D] £1500, Abbey Lodge of Westminster £100, Welconstruct Trust £145, Hanover Brokers Insurance Ltd £283.82, Mrs [GRO-D] £58, Anon £50.

It was agreed that the financial position would continue to be reported in this format each month.

(b) Budget 1985: Mr Prothero reported that this would be ready for presentation to the March meeting.

(c) Salary Reviews: Mr Prothero reported that in view of the increased responsibilities being borne by the Co-ordinator the officers wished to propose that his salary scale be increased from point 38 to point 43 on the relevant scale. This, having been proposed by Mr Prothero and seconded by Mr Colthorpe, was agreed unanimously.

85.21

GRANT APPLICATIONS: The Chairman reported that the Grants Committee had met earlier in the evening and wished to make the following recommendations to the Executive Committee for transmission to the next meeting of the Council:-

(a) Dr C A Ludlam, Edinburgh: This application had now been forwarded to the Medical Advisory Panel and their responses received and considered. Members of the panel had recognised a lack of originality in the project, the facility being available at a number of locations. While the value of the project was not being questioned it achieved a low priority in comparison to the pressing work on AIDS which demanded financial support from the Society. The Committee therefore proposed, particularly in view of the strong support from the Reference Centre Directors supporting the following applications at (b) and (c), not to support Dr Ludlam's request.

(b) Dr Richard Tedder: These applications, made as a result of strong (c) Dr Philip Mortimer: overtures from the Reference Centre Directors, were concerned with the ongoing testing for HTLV III seropositivity and identification of the precise meaning of that test. These two virologists work in close collaboration and their combined work is of the utmost importance to every person with haemophilia throughout the UK and further afield. The grants sought were as follows:

	Capital		Revenue
	£5,725	up to	£9,796
Dr. Tedder		up to	£9,796
Dr. Mortimer			



Both applications were for one year's funding in the first instance although it was recognised that there might be need for further funding. It was recommended that this application succeed.

(d) Miss Campbell, PHLS: Miss Campbell requested a grant to enable her to attend the CDC Conference on AIDS in Atlanta, Georgia. Since this was by way of advancing her academic career only it was recommended that the application fail.

(e) Dr E E Mayne, Belfast: Dr Mayne applied, with the unanimous support of the Northern Ireland Group, for a grant of £1,170 to enable her to continue to employ a part-time physiotherapist at the Royal Victoria Hospital. A grant had been agreed in 1982 but because of various delays the appointment had not commenced until January 1984. It had not been possible to establish hospital funding during 1984 which was why this request was now before the Society. In view of the low cost and the great benefit to members in Northern Ireland it was recommended that the application succeed.

(f) Dr E G D Tuddenham, Royal Free Hospital: Some time ago Tayside Group were given £500 to support work connected with genetic engineering. Dr Tuddenham had applied for a grant of £297.78 for the purchase of a piece of equipment - a column synchropak - for use in connection with his work on synthetic factor VIII. It was recommended that his application succeed, especially in view of the fact that the money was available and earmarked within the Research Fund.

(g) Dr R T Wensley, Manchester: Dr Wensley had submitted an application for a grant of £5000 per year over two years for investigation into the increased efficiency of collecting plasma in heparin rather than citrate solutions. It was recommended that the application be referred to our medical advisors for further advice. That those recommendations be adopted was approved nem con.

85.22

WORLD FEDERATION OF HEMOPHILIA: There was nothing to report.

85.23

LOCAL GROUPS/SOCIETY REPRESENTATIVES: The Co-ordinator reported that:

(a) Mr GRO-D had accepted appointment as Society Representative for Devon and Cornwall and that Mr GRO-D had accepted appointment as Society Representative for Sussex.

(b) Following a visit to a large group of patients and parents in Portsmouth, he wished to recommend that a local Group be set up there. This was agreed unanimously for recommendation to the next meeting of the Council.

(c) Scottish Group wished the Society to sponsor an application under Section 10 of the Social Work (Scotland) Act 1968, for the appointment of a Social Worker to serve the Glasgow Haemophilia Centre. Since various papers from Mr Cowe had not arrived in time for the meeting and there was a strong possibility of employer's responsibilities, it was agreed to defer discussion and delegate the matter to the officers for further discussion on 19 February.

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(d) Following the last meeting of the Council the North West Group had made a submission to the Executive Committee deploring the increase in the membership subscription and the handling of that subject and also commenting on the proposed Central Funding. The Executive Committee gave their unanimous approval to the letter sent by the Co-ordinator to Mrs Guy upon receipt of the submission and felt that further action was unnecessary.

- 85.24 1985 ANNUAL GENERAL MEETING: After discussion it was agreed that the 1985 AGM should be held in London (on Saturday 1 June as agreed) and that Dr. Forbes ( along with Dr. Richard Tedder) be invited to address the afternoon session on the subject of AIDS. *Asi*
- 85.25 CO-ORDINATOR'S REPORT: The Co-ordinator reported that an application for a Section 64 grant from the Department of Health and Social Security had been filed. The outcome may not be known for some time.
- 85.26 ANY OTHER BUSINESS - There was no other business
- 85.27 DATE AND PLACE OF THE NEXT MEETING: Thursday 14 March 1985 in the Senator Room at the Kennedy Hotel, London, NW1 at 6p.m. for 6.30p.m.

Approved on 14 March 85 as an accurate record of proceedings.

Signed GRO-C Chairman