



PATRON: H. R. H. THE DUCHESS OF KENT

# THE HAEMOPHILIA SOCIETY

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MINUTES OF THE MEETING OF THE COUNCIL OF THE HAEMOPHILIA SOCIETY held on Saturday 24 November 1984 in the President Room of the Kennedy Hotel, London NW1.

Those present:

The Revd. A J Tanner, Mr D Rosenblatt, Mr K Milne,  
Mr J Prothero, Mrs M I Britten, Mr K Colthorpe,  
Mrs C Holliday, Mr C Knight, Dr. L Kuttner, Mrs D Lewis,  
and representatives of the following Groups:-  
Birmingham, Cambridge, Colchester, East Kent, Jersey,  
Leicester & Rutland, Lewisham, Lincoln & District,  
Merseyside & District, Norfolk & Norwich, Northampton  
& District, North Eastern, Northern Ireland, North  
Wales, North West, Oxford, Scottish, Sheffield, Southern,  
South Essex, Tayside  
In attendance: D G Watters (Co-ordinator)  
Miss I Hawkins (Personal Assistant)

## AGENDA

- 84.30 Apologies for absence
- 84.31 Minutes of the meeting held on 15 September 1984
- 84.32 Matters arising
- 84.33 Treasurer's Report
- 84.34 Research Grant Applications
- 84.35 World Federation of Hemophilia
- 84.36 Society Representatives
- 84.37 Matters from the morning session
- 84.38 Any other business
- 84.39 Date & place of next meeting

84.30 APOLOGIES FOR ABSENCE: were received from Mr Abrahams, Mr Wetherell and representatives of the Bristol, Sussex, South Wales and Northern Group.

84.31 MINUTES of the meeting held on 15 September 1984: the adoption of those minutes as an accurate record of proceedings at that meeting were proposed by Mr GRO-A, seconded by Mrs Holliday and agreed unanimously.

84.32 MATTERS ARISING

(a) AIDS: This subject had received detailed consideration at the morning session (See Appendix 1 to these minutes) and the following courses of action for Groups and individuals were approved by those present:

- (i) Demand that heat-treated product now from Centres - this is possible on a named patient basis.
- (ii) Ensure the Transfusion Centres maintain the highest possible standards in blood collection. Members were recommended to visit their local transfusion centres and to let Trinity Street know if no AIDS leaflets, etc, are on display.
- (iii) Immediately write to their MP's about AIDS-risk, heat-treatment and plasma collection (as detailed in Appendix 1)

(b) Overseas Sub-Committee: The Chairman reported on the visit to London by Dr. Jain on 29 November, prior to his return to India. He had been training under Professor Mannucci in Milan and an invitation was extended to all to come to meet him at Trinity Street.

(c) Blood Products Sub-Committee: Mr Milne, Chairman of this Sub-Committee, had nothing to add to his earlier contribution to the discussion on AIDS (see Appendix 1).

84.33

TREASURER'S REPORT: The financial position of the Society had received detailed consideration at the morning session - see Appendix 2 to these minutes. The following points were considered:

(a) Research Appeal: After careful consideration it was agreed, with one abstention, that the Research Appeal be closed. This had been proposed by Mr Prothero, seconded by Mr GRO-A.

(b) Annual Subscription: Having established, by a clear majority, that this question could be decided by today's meeting (19 votes for, 7 against) it was agreed that from 1 January 1985 the annual subscription would be raised to £5. 2 votes were cast for £12 p.a. 24 votes for £5 and 4 votes for £2.50 p.a. Those responsible for drafting the revised applications were invited to use careful wording when describing free subscription.

(c) Centralised Funding: The Finance Sub-Committee were asked to give careful consideration to all aspects of centralised funding and to have this as a fully documented agenda item for the next meeting of the Council. Mr GRO-A will provide information on a scheme operated by one of the banks.

(d) Group accounting: The supreme importance of each and every Local Group providing accounts up to 31.12.84 was stressed by several Council members and it was emphasised that ALL Groups must provide this before the last day of February 1985. Council members expressed their profound regret that certain Groups had only provided their accounts to 31.12.83 within the past few weeks.

(e) Reserves held by Groups: Although no firm ruling was made on the matter, Groups were asked to look closely at whether or not they needed to hold as much as £1,000 (the present maximum) in their accounts.



(e) Continued

The Treasurer will be writing to all Groups in this connection.

(f) Forward Forecasting: The importance of forward forecasting was emphasised and the Finance Sub-Committee were asked to prepare this with effect from 1 January 1985.

The Chairman proceeded to receive cheques from Local Groups, having first of all reported that since the last meeting of the Council donations had been received as follows:-

South Wales £750, North Eastern £500, Birmingham & Midland £500, Northampton £1,000, Northern Ireland £5,000, North West £1,000, Merseyside £350, Merseyside £150, Sussex £142.

Cheques were then received as follows:-

North Wales £250, Birmingham £1,000, Lincoln £900, South Essex £250, Scottish £1500, Southern £1500, Cambridge £500, East Kent £1000.

84.34

RESEARCH GRANT APPLICATIONS:-

The Chairman reported that the Research Grants Committee have given careful and detailed consideration to the following grant applications and have reported on their findings to the full Executive Committee. Their deliberations have been based on the merit of the applications and coupled to the financial constraints which must apply at the present time.

(a) Dr F E Preston, Sheffield: Dr Preston had applied for a grant of £5,672 for one Junior MLSO to work on a project involving a study of the influence of factor VIII multimers of clotting factor concentrates on the behaviour of factor VIII following infusion. The application had been referred to the Medical Advisory Panel by the last meeting of the Council and their responses had been received and analysed. No member of the panel gave this project a high priority rating and none regarded it as highly original work. The majority of recommendations opposed the award of a grant. The project was originally funded (revenue) by a pharmaceutical company who have withdrawn their support. The reason for this is not known and Dr Preston did not allow us to contact the company concerned.

The Executive Committee were unanimous in their recommendation that no grant be awarded. This was confirmed, nem con, following proposal from the Chair.

(b) Dr F G H Hill, Birmingham: This application was for a grant of £6,800 to enable him to continue the employment of his Research Social Worker. The Society had already funded this project for one year. While the Executive Committee recognised the very real value of the work achieved by the post-holder and believed that there was an undisputed need for such a worker in each and every Haemophilia Centre dealing with large numbers of young parents,

## (b) Continued.

there was an underlying view that those posts should not be funded from the limited resources available from the Society and the issue should be viewed more widely in the context of statutory funding and pressures which can be brought to bear on the relevant authorities. The Council were informed that there were at least three further applications of a similar nature which are about to be presented to the Society.

In view of considerable variation in the opinions expressed by members of the Executive Committee, this application was presented to the Council with no recommendation. Following discussion it was agreed that this grant be paid for one further year.

(c) Dr C A Ludlam, Edinburgh: Dr Ludlam had made an application for a grant of £16,000 (over two years) for the establishment of a gene probe library in Edinburgh, based on the existing library at The Western General Hospital there. The application was identical in almost all respects to the work being carried out at Cardiff by Dr Ian Peake's team and for which the Society refused a grant earlier this year. While the establishment of such libraries had undisputed merit, all Supra-Regional Centres will be establishing them in the near future and this application was treated in a similar light to the application of Dr Peake which, after referral to the Medical Advisory Panel, was turned down. The recommendation of the Executive Committee was therefore that no grant be made in response to this application. After discussion it was agreed to refer the application to the Medical Advisory Panel.

*Since it was recognised that this application was fundamentally different in methodology from Dr Peake's application*

(d) Dr A Aronstam, Alton: Dr Aronstam had applied for a grant of £3,883.10 for the purchase of a Wolf Intra-articular surgery set for use in orthopaedic surgery associated with, among other things, haemophilia. The Executive Committee recommended that no grant be made and this was endorsed unanimously by the Council.

- 84.35 WORLD FEDERATION OF HEMOPHILIA: There was nothing further to report.
- 84.36 SOCIETY REPRESENTATIVES: The Co-ordinator had circulated the proposals for this new development in the life of the Society (see Appendix 3). Those were accepted unanimously.
- 84.37 MATTERS FROM THE MORNING SESSION: There were no matters from the morning session not already covered by these minutes.



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84.38

ANY OTHER BUSINESS: No other business had been notified. Mrs  
[GRO-A] requested that the National Annual Draw be held earlier  
in the year since it had affected the North Eastern Group's own  
draw. While this was noted, it was pointed out that the National  
Draw had taken in excess of £8,000 this year.

84.39

DATE AND PLACE OF NEXT MEETING: Saturday 9 March 1985 during the  
Residential Seminar at The Heathlands Hotel, Bournemouth.

Approved on \_\_\_\_\_  
of proceedings.

\_\_\_\_\_ as an accurate record

Signed \_\_\_\_\_

[GRO-C]

\_\_\_\_\_ Chairman

## APPENDIX 1

### AIDS

The Chairman introduced this as the first item on the morning agenda of the Council meeting. He outlined briefly the action taken by the Society to date with particular reference to the forthcoming meeting with the Minister. The Chairman stressed that despite the media coverage of the past week, nothing had changed.

Mr Knight outlined the response which the Society had been able to make to the media coverage and how it had been possible to "use" the media to make political mileage. This was illustrated by a statement which had been prepared early on Monday morning and which had been made available to the national press. It had been possible to get some of the points which will be raised with the Minister into the media and the complete list is as follows:

1. That since the DHSS have recognised heat-treated product as important enough to bring into production from April 1985 (in small quantities), immediate steps should be taken to import supplies to treat everyone now. The Government will be asked to do this irrespective of cost.
2. The Government will be asked to introduce national plasmapheresis programmes to ensure self-sufficiency by 1986. It was noted that while Blood Products Laboratory will have the capacity to achieve self-sufficiency by 1986, the strong evidence was that adequate supplies of plasma could not be obtained otherwise than by plasmapheresis.
3. Because of the apparently careless way in which some Transfusion Centres have handled the collection of blood since the AIDS scare began, we will urge that situation to be changed and that the development of the test for the presence of HTLV-III in donors /donated blood and blood products be allowed to proceed without financial constraint.
4. The Society will, with some reluctance, seek core funding for central running costs from the Department.

Mr Knight also outlined the development of the media campaign and placed particular emphasis on the pressures which the office had been under all week. It was anticipated that this could continue for some time.

Those present were asked to communicate the above points to their Groups and ask people to write to their MP's along the lines outlined in 1-4 above; ask for heat-treated concentrates at their Centres and also write to the Minister (Norman Fowler) about the current situation.

## APPENDIX 2

### The Financial Situation

Mr Prothero gave a detailed and illustrated analysis of his paper outlining the current financial position of the Society. Copies were available for all members of the Council. This showed a projected shortfall on General Funds again at the end of the year. Mr Rosenblatt outlined the action already taken by the Finance Sub-Committee.

Various suggestions were made at the meeting and those will be considered by the Finance Sub-Committee when it next meets in early December.



## SOCIETY REPRESENTATIVES

### 1. BACKGROUND

The establishment of Society Representatives in areas (or hospitals) where there is no formal Society presence was approved unanimously by the Council at their meeting on Saturday 15 September 1984. There are naturally many details to be evolved before the scheme can be put into operation if it is to present an efficient representation of the Society.

### 2. THE FUNCTION

The Society Representative will represent the Society by:-

- (a) being the local "link" person who will have sound knowledge of local facilities and enjoy a constructive working relationship with the Centre(s) in the area
- (b) collecting donations raised by other bodies - e.g. in Devon & Cornwall the local "Breakers" Club (CB Radio for uninitiated!) has spent the last year raising money for the Society and wants someone representing the Society to collect the money and make a speech
- (c) where possible, responding to requests for any information regarding members to assist the Case Committee with its work
- (d) being the local "information provider" for leaflet dispensers etc.
- (e) dealing with local issues which require attention, but always in consultation with the Society's Co-ordinator
- (f) presenting views on treatment facilities to the Society through the Co-ordinator
- (g) where necessary, putting members in an area in touch with each other
- (h) encouraging the aims and objects of the Society in every way possible

### MODUS OPERANDI

- (a) The position of Society Representatives is a purely honorary one
- (b) The Society Representative has no power to open bank accounts in the name of the Society
- (c) The Society Representative is not empowered to incur expenditure on behalf of the Society
- (d) Any monies raised for, or collected on behalf of, the Society, should be forwarded to Trinity Street as quickly as possible

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- (e) Reasonable and minimal costs will be met by the Society - e.g. occasional postage, telephone or, exceptionally, approved travel costs. Where ever possible mailings should be carried out through the Society's offices. Bearing in mind the honorary and voluntary nature of the work, claims should be minimal
- (f) Society Representatives will meet twice each year, in March at the Residential Seminar and at the September meeting of the Council. They will have no formal representation on the Council of the Society
- (g) Information and communication services will be provided to Society Representatives through the Co-ordinator to whom they will be immediately responsible

David G Watters  
4 October 1984