

Witness Name: Katherine Victoria Burt
Statement No: WITN6392001

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INFECTED BLOOD INQUIRY

WITN6392068



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 15 September 1984 at 11 a.m. in the President Room of the Kennedy Hotel, London, NW1.

Those present: The Revd.A.J.Tanner (Chairman), 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, Mr.P.Wetherell and representatives of the following Groups:- Birmingham, Bristol and South West, Cambridge, Colchester, East Kent, Jersey, Leicester & Rutland, Lincoln & District, Norfolk and Norwich, Northern, Northampton, North Eastern, Northern Ireland, North Wales, North Western, Oxford and District, Scottish, Sheffield, South Essex, South Wales, Sussex, Tayside.

In attendance: D.G.Watters (Co-ordinator)
Miss.I.Hawkins (Personal Assistant)

AGENDA

- 84.20 Apologies for absence
- 84.21 Minutes of meeting held on 23 June 1984
- 84.22 Matters arising
- 84.23 Research Grants Applications
- 84.24 World Federation of Hemophilia
- 84.25 Blood Products Sub-Committee
- 84.26 Honorary Treasurer's Report
- 84.27 Matters from the morning session
- 84.28 Any other business
- 84.29 Date and place of next meeting

84.20 APOLOGIES for absence were received from Dr.J.F.Wilkinson, Mrs.Lewis, Mr.Abrahams, and Merseyside, Lewisham and Southern Groups.

84.21 MINUTES of the meeting held on 23 June at Manchester, which had been circulated in advance, were unanimously approved as an accurate record of proceedings, following a proposal by Mr.Cowe, seconded by Mr.Colthorpe.

84.22 MATTERS ARISING:

(a) AIDS: The Chairman reported that the Executive Committee continued to monitor the AIDS situation in the UK as it affects people with haemophilia. That situation remains unchanged and a new HAEMOFAC will appear in the next week or so.

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(b) Overseas Sub-Committee: The Chairman reported that the doctor from Delhi had almost completed his training under Professor Mannucci in Milan. The Lions Club of New Delhi had undertaken to pay his salary costs. The Chairman also reported that GRO-D from Sheffield had made it possible to provide, at no cost, an aggregometer and an electrophoresis tank. The thanks of the Society were recorded to GRO-D his colleagues and Sheffield Group for their productive enthusiasm in co-operating with this vital development in the work in India. A discussion will be held with Professor Mannucci at the UK Centre Directors' Meeting next week and thereafter the list of requirements will be re-circulated to Groups.

84.23

RESEARCH GRANT APPLICATIONS: Details of the grant applications had been circulated earlier in the day and the Chairman introduced each of the following applications:-

(a) Dr.G.Savidge, St Thomas' Hospital, London: This application, for the extension of a grant approved in 1983 for one year, requested further funding of £10,000 for a further year. The object of the study is to continue work on cell mediated immunity in haemophiliacs. The application had been referred to the Medical Advisory Panel who presented a divided opinion. The recommendation from the Executive Committee was that no grant be awarded since it was felt that the work, while valuable, was standard and should now be funded from hospital or health authority budgets. This recommendation was approved unanimously, having been proposed by the Chairman and agreed nem con.

(b) Dr.F.E.Preston, Royal Hallamshire Hospital, Sheffield: This application, for the study of factor VIII multimers of clotting factor concentrates on the behaviour of factor VIII following infusion, was recommended for referral to the Medical Advisory Panel. That this course be followed was approved unanimously following proposal by Mrs. Britten, seconded by GRO-D

(c) GRO-D, University of Cambridge: This application requested £500 travel costs for a PHD Student to travel to Toronto, Canada, in order to study a colony of haemophilic dogs and work being carried out there on antibodies. The Executive Committee's recommendation was that no grant be awarded and, having been proposed by the Chairman, this was agreed nem con.

84.24

WORLD FEDERATION OF HEMOPHILIA

(a) XVI Congress in Rio de Janeiro: Mr Rosenblatt reported on the recent Congress and his report will be reproduced in a future edition of The Bulletin.

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(b) Other matters: The Chairman asked members to advise the Co-ordinator of any contacts held with Lions Groups in the U.K. with the object of attracting additional support for the work in India.

(c) Mr. Milne expressed appreciation of the Chairman's work for The World Federation of Hemophilia and amidst acclamation presented him with a commemorative mug from the Congress.

84.25

BLOOD PRODUCTS SUB-COMMITTEE: The Council accepted Mr. Milne's report which had been given at the morning session. The main points emerging from this report as follows:-

(i) The development of the Blood Products Laboratory: The Blood Products Laboratory at Elstree was on target for opening in early 1986. While the building would be completed and the equipment installed by that date it was foreseen that there could well be problems with the supply of plasma and this subject would be raised with Lord Glenarthur at a meeting due to be held later in the year.

(ii) Requirement of factor VIII in the U.K.: Mr. Milne expressed some concern that the maximum yield of factor VIII from the new plant at Elstree could fall short of the actual requirement. The requirement of 100 m. units of factor VIII was based on a projection which is now some years out of date. He felt that commercial factor VIII could be required for some years to come - certainly up to the "golden age" of synthesised factor VIII.

(iii) Screening of UK blood donors: Mr. Milne expressed some concern about the apparent lack of screening of donors in the UK which in many cases is less stringent than that imposed by the major commercial companies in the United States. There was, however, the possibility of screening donors for AIDS in the near future.

(iv) Synthetic factor VIII: While there was much development work to be done in connection with the synthesis of factor VIII, Mr. Milne reported that he was now exploring the future use of those products in the UK. Questions arising included whether the Government would be prepared to buy those products, which would almost certainly be manufactured in the USA, having spent some £25 million on the development of Elstree and plasma-based products.

(v) Packaging of NHS factor VIII: Mr. Milne was involved in discussing the packaging of PPL factor VIII but was not optimistic about the outcome of those discussions since there was a major cost implication.

It was noted, particularly from the morning session, that there was a need to clarify the UK position when synthetic factor VIII becomes available commercially and this was noted for future discussions with the Department.

The Chairman thanked Mr. Milne for his report and for all his work as Chairman of the Blood Products Sub-Committee.

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HONORARY TREASURER'S REPORT:

Current Account £2,928.38
 Ordinary Deposit Account £13,416.74
 Special Deposit Account £70,000.00

Mr. Prothero began his report by apologising for not being in a position to produce a statement of the financial position for the six months to 30 June 1984. This will be presented to the Executive Committee in October and the November meeting of the Council.

The Chairman outlined the position as it was seen by the Executive Committee, which was that there was likely to be a deficit on the General Fund again for 1984. This was a natural result of the substantially increased services provided by the Society to the membership in recent years. All expenditure is monitored closely so it is most important to seek ways of increasing income.

A constructive discussion followed during which a range of suggestions was made, including the relationship between the Research Funds and General Funds. Questions were raised regarding funds held by Groups and the possibility of a levy on funds donated for Research being applied to the services of the Society, a policy now adopted by the WFH. Mention was also made of the position of money held in Research Funds in relation to fund raising for the wider work of the Society.

The expenses of some Groups was queried by South Wales Group and stress was laid on the voluntary nature of the work of the Groups. All Groups were asked to donate as much as possible to the Society's General Funds before the end of the year. Groups were asked to give priority to the submission of their accounts as soon as possible after 31 December each year and concern was expressed that some Groups had not yet submitted their accounts to 31 December, 1983.

84.27

MAITERS FROM THE MORNING SESSION: At the morning session detailed consideration had been given to a paper submitted by the Executive Committee regarding the creation of a new structure which would entail the appointment of "Society Representatives" in local areas not otherwise affectively covered by a local Group.

It was proposed by GRO-D

That "Society Representatives" may be appointed:

- (i) in areas where no local Groups exist, and
- (ii) for Haemophilia Centres where there is no formal Society representation.

This was seconded by Mrs Guy and agreed unanimously. The Co-ordinator was asked to prepare a further paper dealing with functions, areas of jurisdiction, etc, to be circulated to all Council members.

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84.28

ANY OTHER BUSINESS:

(a) Following comments regarding fund-raising equipment, the Co-ordinator was asked to look into the position and report at a future meeting.

(b) Mrs. Holliday reported briefly on the 1984 North Wales Adventure Holiday and gave notice that she would be requesting national funding for this venture.

(c) The Chairman proceeded to accept cheques from Groups as follows:

North East Group	£500.00	Research
Northampton	£1,000.00	Research
Birmingham	£500.00	General
South Wales	£750.00	General

These Groups were thanked most warmly by the Chairman for all their hard work and dedication. He again emphasised the importance of supporting the wider services of the Society through its General Fund.

(d) DATES for meetings in 1985 were fixed as follows:-

March 8-10	Seminar and Council (Bournemouth)
June 1	A.G.M. and Council (possibly London)
September 14	Council (London)
November 16	Council (London)

84.29

DATE AND PLACE OF NEXT MEETING: Saturday 24 November at the Kennedy Hotel, Cardington Street, London, NW1.

GRO-C

24 November 1984