

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392072



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 8 November 1984 at the Kennedy Hotel, London, NW1.

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

AGENDA

- 84.117 Apologies for absence
- 84.118 Minutes of the meeting held on 11 October 1984
- 84.119 Matters arising
- 84.120 Case Committee
- 84.121 Research Grants Committee
- 84.122 Report from the Finance Sub-Committee
- 84.123 Blood Products Sub-Committee
- 84.124 Treasurer's Report
- 84.125 World Federation of Hemophilia
- 84.126 Local Groups
- 84.127 Co-ordinator's Report
- 84.128 Any other business
- 84.129 Date and place of next meeting

84.117 APOLOGIES FOR ABSENCE: were received from Mrs Holliday,
Mr Prothero, and Mr Wetherell.

84.118 MINUTES of the meeting held on 11 October 1984. It was noted that
Mrs Holliday was present at that meeting. This amendment having
been made the minutes were approved unanimously as an accurate
record of proceedings at the meeting on 11 October having been
proposed by Mr Knight, seconded by Mr Colthorpe.

84.119

MATTERS ARISING:

(a) R G Macfarlane Award: The Chairman reported that the presentation
of the R G Macfarlane Award to Dr Tuddenham by Professor Macfarlane
had been a most happy occasion. The gratitude of the Society
had been expressed to Professor Macfarlane and to all those
concerned with the arrangements at the Royal Free Hospital.

(b) AIDS and 'The Mail on Sunday': Having considered the reply
from Paisner and Company it was agreed that the Co-ordinator
should write a short letter to the Managing Editor of 'The Mail
on Sunday' pointing out the misleading nature of the article so
far as it concerned his views or those of the Society.

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(c) Presentation to GRO-D. The arrangements were re-iterated for the benefit of those attending.

(d) Classification of Haemophilia Centres: The Chairman reported that Mr Knight and Mr Milne would represent the Society on the Sub-Committee of the Centre Directors' Organisation set up to look into this question.

(e) Annual Residential Seminar: After discussion it was agreed to ask Dr Aronstam to give the annual Society lecture at the 1985 Seminar. The question of contribution to costs was deferred for further consideration by the Seminar Sub-Committee.

(f) St Thomas' Hospital: The Chairman reported that the Sub-Committee appointed at the last meeting of the Executive Committee had met the Administrator of St Thomas' and was due to meet again the next week to formulate its strategy for improving facilities at the hospital. A more detailed report would be available at the December meeting of the Executive Committee.

84.120

CASE COMMITTEE: Mr Rosentblatt reported that the Case Committee had met earlier in the day and presented the following recommendations to the Executive Committee:-

(a) A grant of £50 towards the cost of a Christmas Party for the haemophilic children at Great Ormond Street hospital

(b) A grant of £100 to a member in Wales to assist with general financial problems

(c) A grant of £75 to a member with Von Willebrand's Disease in the North East to assist with hardship following a road accident

(d) A grant of up to 50% of telephone installation costs for a severe haemophiliac living in the North West

(e) A grant of £50 to a member in the West Country to assist with general hardship, the grant being conditional upon co-operation with the Society in sorting out various issues

(f) A grant of £50 to assist with general hardship being suffered by a member in the Home County following the collapse of his business and prior to State benefits being available (This grant is also subject to the condition that the member co-operates with the Society in making appropriate arrangements to deal with other matters also).

(g) A grant of £50 to assist a family in the West Country with two haemophilic boys following a period of acute hardship occasioned by the older boy's haemophilia

84.121

RESEARCH GRANTS COMMITTEE: The Chairman reported that the Research Grants Committee had met earlier in the day and wished to present the following recommendation to the Executive Committee:-

(a) Dr Preston, Sheffield: Having considered the replies from the Medical Advisory Panel, The Research Grants Committee were unable to recommend support for this project. The work involved research into the structure of Factor VIII, including the relationship between Factor VIII multimers and their survival in the Factor VIII complex following infusion.

(b) Dr Ludlam, Edinburgh: Dr Ludlam had submitted an application immediately after the last meeting of the Executive Committee for work involving the detection of haemophilia A & B with gene probes by linkage analysis. Since this application was identical to that refused unanimously by the Council in response to an earlier application from another Centre at the June meeting of the Council, the Grants Committee were unable to recommend that a grant be made.

Both these proposals were adopted nem con having been proposed by the Chairman.

(c) Dr F G H Hill, Birmingham: Dr Hill had applied for a grant of £6,800, for one year, to enable his part-time Research Social worker to remain in post until all the necessary steps have been taken to secure permanent statutory funding. After discussion it was agreed unanimously that the application should be presented to the council without any recommendation in order that the Local Group might speak to the application. There was a great amount of sympathy for Dr Hill's application and admiration for the work done so far.

(d) Dr Tuddenham re Pakistan: Dr Tuddenham had not provided the requested information.

84.122

REPORT FROM THE FINANCE SUB-COMMITTEE: Mr Rosenblatt reported on the meeting of the Finance Sub-Committee which had taken place since the last meeting of the Executive Committee. Following Mr Rosenblatt's detailed report it was once again emphasised that the way ahead was to expand income, although we should continue to examine ways of reducing costs but not to the extent of curtailing the present services provided by the Society.

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It was agreed that:-

- (a) The Sub-Committee would examine further the matter of increasing subscriptions and membership generally
- (b) The external Fund-Raising Committee would be set up under the convenorship of Clive Knight. This was dependent upon advice from advertising and public relations personnel and the completion of a document which sets out the job description of the Society
- (c) Mr Livingstone-Booth, former Director of the Charities Aid Foundation would be called in to advise on tax concessions, etc
- (d) A letter would now be sent to all Groups asking for the maximum possible contribution to central funds before the end of the current financial period
- (e) Consideration of savings on meeting expenses be pursued, this to include all aspects of travel costs
- (f) Mr Prothero and Mr Rosenblatt would present the above to the Council meeting on 24 November in greater detail and Mr Prothero's paper, presented at the October Executive Committee meeting would also be available there

84.123

BLOOD PRODUCTS SUB-COMMITTEE: Mr Milne summarized the contents of his paper which was tabled at the October meeting of the Executive Committee and explained the possibilities for the development of the facilities at the Blood Products Laboratory at Elstree, along with the present financial and practical constraints on such developments. It was agreed that financial limitations must be discussed with the Minister. Mr Milne explained that he would now submit his paper to the Medical Advisory Panel for comment and that he would also invite Dr Kernoff's opinion. In reply to a question from the Co-ordinator, the Executive Committee confirmed that there was no medical evidence available to show that UK product, were in any way "safer" than imported ones, particularly from hepatitis or AIDS risk.

84.124

TREASURER'S REPORT: The Co-ordinator reported on behalf of Mr Prothero as follows:

Special Deposit Account	£70,000
Ordinary Deposit Account	£7,416.74
Current Account	£10,488.80

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The following donations had been received since the last meeting of the Executive Committee:-

Mrs GRO-D £1,000, Executors of GRO-D (deceased) £7,581.36,
Mr GRO-D £117, GRO-D £110, Northern Ireland Group £5,000,
Good Neighbours Trust £1,000, Mr & Mrs GRO-D £50, Harold
Amelan Charitable Trust £175, Miss GRO-D £200, Anon £50

ANNUAL DRAW stood at :£2,897.90, with the most productive period to come, and the benefit of a reminder Bulletin which members would receive in the coming week.

BANKINGS since the last meeting totalled £21,978.96

84.125

WORLD FEDERATION OF HEMOPHILIA:

(a) Overseas Sub-Committee: The Chairman reported that this Sub-Committee had met to discuss the question for ongoing support for the work in Delhi. It was reported that the doctor, who was currently being trained for work at the Centre by Professor Mannucci, would be passing through London in the next few weeks and would want to meet members of the Executive Committee. The Co-ordinator reported that he had received offers of equipment from a few hospitals.

(b) Use of WFH logo by Dr Aronstam: Following advice from Montreal it was formally agreed that the WFH logo could now be used on the front cover of Dr Aronstam's book.

84.126

LOCAL GROUPS: The Co-ordinator reported that he had attended the AGM of the Northern Ireland Group where he had been presented with a cheque for £5,000 for the funds. He also reported that it seemed likely that the Colchester Group would close quite soon. Mrs Lewis reported on her attendance at the North West Groups AGM. Mr Milne also reported on his attendance at the Lincoln Group's AGM.

84.127

CO-ORDINATOR'S REPORT: There was no report.

84.128

ANY OTHER BUSINESS:

(a) Study Day at Lord Major Treloar: Dr Kuttner would attend.

(b) Mr Knight requested that the question of the re-structuring of Executive Committee meetings be placed on the December agenda.

84.129

DATE AND PLACE OF NEXT MEETING: NB Thursday 6 December 1984 at 6 p.m. for 6.30 p.m. in the President Room at the Kennedy Hotel, London, NW1.

Approved on 6 December 1984 as an accurate record of proceedings.

Signed

GRO-C

Chairman