

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392083



**The
Haemophilia
Society**

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**MINUTES OF THE MEETING OF THE EXECUTIVE COMMITTEE OF THE
HAEMOPHILIA SOCIETY**

held on Tuesday 7 July 1987 at 123 Westminster Bridge Road

Present: The Reverend Alan Tanner, Mr Milne, Dr Kuttner, Mr Colthorpe, Mr Cowe,
Mrs Daniel, Mr Fitton, Mr Kirman, Mr Stevens and Mr Taylor.
In attendance: Mr Watters (General Secretary)

A G E N D A

- 87.37 Apologies for absence
- 87.38 Minutes of the meeting held on 8 June 1987
- 87.39 Matters arising
- 87.40 Working Party reports
- 87.41 World Federation of Hemophilia
- 87.42 General Secretary's report
- 87.43 Any other business
- 87.44 Date and place of next meeting

87.37 **APOLOGIES FOR ABSENCE** were received from Mr Knight and Mr Prothero.

87.38 **MINUTES** of the meeting held on 8 June 1987, which had been circulated in advance, were unanimously agreed as an accurate record of proceedings at that meeting.

87.39 **MATTERS ARISING**

- (a) **The Presidency:** The Chairman reported that no further progress had been made towards the nomination of a new President for the Society.
- (b) **Parliamentary Campaign:** Simon Taylor reported on the situation currently affecting the Parliamentary Campaign. Due to pressures of the Parliamentary Timetable, and the shortness of time between the reconvening of The House, after the General Election, and the summer recess, it had been decided to delay our presentation to MPs until mid-October. In the meantime, a meeting was being sought, on a basis of some urgency, with John Moore the new Social Services Secretary.

The booklet produced by Dr Peter Jones had been prepared and copies had been submitted to the Secretary of State for Social Services.

[ST] It was also agreed that every effort should be made to attend the Party Conferences, when they are held later in the summer. Simon Taylor would mastermind this operation.

[P&ER] In connection with the development of the Parliamentary Campaign, it was agreed that the job description for the AIDS Co-ordinator should be redefined to take account of the political 'leg work' which would have to take place in advance of a detailed campaign in mid-October. Following discussion, it was proposed by Simon Taylor, seconded by George Kirman, and agreed unanimously, that the Publications and External Relations Working Party be empowered to

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prepare the job specification, advertise and appoint the AIDS Co-ordinator for, in the first instance, a one year appointment.

- (c) AIDS: While there was nothing new to report on a medical basis, the General Secretary commented on the recent ITN Newscast which had reported the situation affecting three boys with severe haemophilia in the USA. Complaints about this item had been made to ITN and the Chairman of the Independent Broadcasting Authority.

87.40

WORKING PARTY REPORTS

- (i) Membership of Working Parties: Following proposals by the Chairman this was agreed as follows:

- (a) Finance and General Purposes

John Prothero, Peter Stevens and Matthew Dodson (Auditor)

- (b) Blood Products

Ken Milne

- (c) Treatment and Care

Ken Milne, George Kirman and GRO-D (co-opted)

- (d) Case Committee

John Prothero, Dr Kuttner and a co-opted Social Worker

- (e) Overseas

The Chairman, Ken Milne, Simon Taylor and Mrs Britten (co-opted)

- (f) Publications and External Relations

The Chairman, Peter Stevens, Andy Cowe, Simon Taylor, Clive Knight and GRO-D (co-opted)

- (g) Seminar

Diane Daniel and Terry Fitton

- (h) Sales

Keith Colthorpe

- (i) Group Liaison

George Kirman assisted by Terry Fitton

- (j) Research Grants

Officers

- (ii) Reports from Working Parties:

- (a) Finance and General Purposes Working Party: This Working Party had not met and Mr Prothero was not present at the meeting, being in Brussels for the ISTH meeting. The Chairman expressed concern that no budget had yet been produced for 1987.

It was confirmed that the accounts package was not yet in operation, for a number of practical reasons. It was agreed that the F & GP should meet as soon as possible to consider the preparation of budgets and the implementation of computerised accounting.

- (b) Blood Products: Mr Milne reported that he was to visit the Blood Products Laboratory at Elstree on 8 July 1987. He would report accordingly thereafter.

- (c) Treatment and Care: Mr Milne reported that this Working Party had met and that a written report would be circulated within the next few days. Mr Milne stressed the value of the welfare rights advocacy, undertaken by the General Secretary, as one of the most important aspects of the Haemophilia Society's work and, in spite of the fact that that was enormously time consuming, the Treatment and Care Working Party wished to stress the importance of the work in the life of the Society.

- (d) Case Committee: Dr Kuttner reported that the Case Committee had met in May and considered 18 applications for financial assistance. Of those, 10 grants were awarded totalling £1,376 - an average of £125.09. In June the Case Committee had considered 22 applications for financial assistance and 17 grants were awarded in the total sum of £2,863.95 - an average of £168.47.

After discussion it was agreed that the Case Committee, in addition to their present powers to grant up to £300 without reference to the Executive Committee, be further empowered to meet the funeral costs involved in AIDS-related deaths, without further reference to the Executive Committee. This was proposed by Peter Stevens, seconded by Andy Cowe, and agreed unanimously.

[F&GP]

The Executive Committee also asked that the Finance and General Purposes Working Party establish a budget in respect of the North Wales Adventure Holidays and report back to the next meeting.

- (e) Overseas: There was nothing to report.
- (f) Publications and External Relations: The recent Bulletin and HAEMOFACT were noted and Simon Taylor promised to produce the Databank as soon as possible. It was also noted that the Committee had considered a proposal regarding children's publications and the establishment of a permanent poster display. The former would be advertised in the next edition of UPDATE and the matter of the permanent poster display was rejected, for the time being, in view of the cost and time element involved in its co-ordination.
- (g) Seminar: Mrs Daniel reported that she had discussed the proposal for mini-seminars with Social Workers in Cardiff who, in turn, would discuss it with their patient-groups. She was currently considering the possibility of a combined one-day seminar for Cardiff/Bristol/Oxford, at a central point for those Centres. She also felt that a similar provision for London was urgently needed.
- (h) Sales: Mr Colthorpe reported that the cost of printing the Christmas Card Brochure had increased from £600 to £1,100 following a misunderstanding about the number of transparencies involved in the production. Mr Colthorpe proposed that the Executive Committee agree to this increase in expenditure. This was seconded by Peter Stevens and agreed with two abstentions.
- Mr Colthorpe agreed that the gift catalogue results had not been as satisfying as he had hoped. It was suggested that March was not the best time of year to launch such a matter.
- The provision of 1987 Business Christmas Cards was noted and it was hoped that this would prove to be a successful venture.
- (i) Group Liaison: George Kirman reported that he would be meeting Terry Fitton on Friday evening to discuss matters affecting a Management Course for Group Members. It was noted that no response had been received to a proposal made to the Group referred to at 87.15 (i) and consequently no further action would be taken in this matter by the Executive Committee.

[DW] Correspondence had been received from the Officers of the Tayside Group, in which they expressed disquiet about the way in which the new Perth Group of the Society had been established. While the Executive Committee recognised that better communication on the subject might have been advisable, they were, nonetheless, firmly of the opinion that since the Perth Group emanated from the enthusiasm centering on the Perth Charity Shop, two Society members and their helpers, the evolution of a Group there was inevitable. It was agreed that the General Secretary should reply to this correspondence from the Tayside Group in those terms.

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[ECC] Further discussion centred on the Constitution of the Society and the practicalities of the ~~growing~~ number of Local Groups. It was agreed that this matter should be considered as an Agenda Item for the Executive Committee Conference.

[P&ER] The General Secretary also mentioned the difficulties being experienced by some Group Officers in the matter of claiming expenses. The Finance and General Purposes Working Party were asked to give this detailed consideration and report to the September meeting. It is hoped that the Working Party will establish criteria for Group expenses and establish mileage allowances, etc.

(j) Research Grants: The General Secretary reported that two applications for Financial Assistance had been received, and considered by the Officers earlier in the evening.

- [DW] (i) Professor M E J Curzon, Professor of Child Dental Health and Preventive Dentistry, Leeds: Professor Curzon had applied for a grant in the sum of £14,623, spread over a two year period, to investigate the quality of dental care in children with haemophilia and conduct a survey of attitudes to this by patients, parents and dentists. This would serve to improve dental care and the well-being of people with haemophilia and related haemostatic disorders. While the Officers felt that this was a worthwhile project they wished to know whether Professor Curzon had made applications to other sources and the General Secretary was asked to follow this up.
- (ii) Dr D N Whitmore, Lewisham Haemophilia Centre: Dr Whitmore had applied for a grant of £1,500 towards re-equipping the new Haemophilia Centre at Lewisham Hospital. The application had the whole-hearted support of the Lewisham Group of the Society who had already earmarked funds which they had contributed to the National Society. On this basis it was unanimously agreed that it be recommended to Council that a grant be made.

87.41 **WORLD FEDERATION OF HEMOPHILIA**

(a) Jubilee Committee: The Chairman reported that he had received a number of ideas to mark the 25th anniversary of the Federation. Those included:-

- (i) The commissioning of a history of the World Federation of Hemophilia
- (ii) A souvenir item such as a paper weight
- (iii) A suggestion that at least one person with haemophilia from each National Member Organisation should attend the Madrid Congress

All those items will be subjects of further consideration.

(b) General Matters: The Chairman reported that he would be attending the ISHT meeting in Brussels on 9 and 10 July and, later in the month, attending an Executive Committee meeting of the Federation in Montreal.

87.42

GENERAL SECRETARY'S REPORT

- (a) Visit to WFH in Canada: The General Secretary thanked the Executive Committee for allowing him time to attend a meeting, with his opposite numbers from Canada and the United States of America, in Montreal during June. The group had been privileged to hold their meetings in the WFH offices and Mrs Schnabel had taken part in their discussions which, largely, had centred on the planning of a Workshop for the Madrid Congress. In addition, discussions had, naturally, been held about the future administration of the Federation itself.
- (b) XVIII Congress: The General Secretary asked that the Executive Committee determine the number of delegates likely to be sent to the Madrid Congress and, in addition, establish the voting member for the Council meeting, so that the person so appointed could be well briefed, in advance, on all aspects of the Council business. It was agreed that six delegates from the UK would be funded to attend - three from Local Groups and three from the Executive Committee. It was noted that GRO-A (North Wales) was automatically entitled to a place, as was Keith Colthorpe. In addition, Mr Milne, Mr Kirman and Mr Taylor indicated that they wished to attend. It was agreed that Mr Milne should be the 1988 voting delegate.
- (c) St Thomas' Hospital: The General Secretary had received a request from the HIV Counsellors at St Thomas' for a grant of £100 to help with the funding of a meeting for patients. That this be granted was proposed by Ken Milne, seconded by Keith Colthorpe, and agreed unanimously.
- [DW] (d) Hand rail: It was agreed that a hand-rail should be fitted to the entire length of the stairs and, further, that the top landing and stairs be redecorated as soon as possible.
- [F&GP] (e) Communication: The General Secretary gave notice that he would be asking the Finance and General Purposes Working Party to investigate the question of the provision of FAX for the Society. The Canadian and American Hemophilia organisations, as well as the World Federation, were contemplating the installation of such equipment in their offices. This matter was referred to the Finance and General Purposes Working Party.

87.43

ANY OTHER BUSINESS

This minute is recorded separately.

87.44

DATE AND PLACE OF NEXT MEETING

Thursday September 10 at 5.30 for 6 pm at 123 Westminster Bridge Road. A PRESENTATION BY TRAVENOL WILL TAKE PLACE BETWEEN 6 PM AND 6.30 PM. It was further agreed that the date of the autumn meeting of the Council be transferred from Saturday 19 September to Saturday 3 October.

Approved as an accurate record of proceedings

Chairman GRO-C: Ken Milne

Date: 10 September 1987 Rev Alan Tanner

87.43

ANY OTHER BUSINESS

- (a) Mrs M I Britten: It was agreed, subject to Mrs Britten's agreement, to fix the date for her presentation dinner as Friday 2 October 1987. The Chairman will communicate with Mrs Britten about the suitability of this date.
- (b) A Haemophilia Society Award: After discussion it was agreed that a new award be established entitled THE HAEMOPHILIA SOCIETY AWARD and that this be presented to persons who provide outstanding service to people with haemophilia.