

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392084**

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**The  
Haemophilia  
Society**

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

**held on Thursday 10 March 1988, at  
123 Westminster Bridge Road**

**Present:** The Revd Alan Tanner, Mr K Milne, Mr J Prothero, Dr L Kuttner, Mr K Colthorpe,  
Mr A Cowe, Mr T Fitton, Mr G Kirman and Mr C Knight.  
**In attendance:** Mr D Watters (General Secretary) and Mr A Brookhouse.

**AGENDA**

- 88.15 Apologies for absence
- 88.16 Minutes of the meetings held on 14 January and 22 February 1988
- 88.17 Matters arising
- 88.18 Working Party reports
- 88.19 World Federation of Hemophilia
- 88.20 General Secretary's report
- 88.21 Any other business
- 88.22 Date and place of next meeting

- 88.15 **APOLOGIES FOR ABSENCE** were received from Mrs D Daniel, Mr P Stevens and Mr S Taylor.
- 88.16 **MINUTES** of the meeting of the Haemophilia Society held on 14 January were approved unanimously, having been proposed by Clive Knight, seconded by George Kirman. Minutes of a meeting of the Executive Committee held on 22 February 1988 were amended at 88.13 by the insertion of the word "permanent" between the words "appropriate" and "salary" in line two of that item and deleting the words "to give him parity with his colleagues". Following that amendment those minutes were agreed unanimously having been proposed by Keith Colthorpe and seconded by Ken Milne.
- 88.17 **MATTERS ARISING:**
- (a) **The Presidency** The Chairman reported that word was awaited from Dr Peter Jones on an approach to Mrs Catherine Cookson. The possibility of Dr Hilary Macfarlane was also mentioned.
  - (b) **Vice-Presidents:** The Chairman reported that he had written to Frank Field, Robert Key and Baroness Masham inviting them to accept invitations to be nominated as Vice-Presidents at the forthcoming Annual General Meeting. The Chairman announced that letters of acceptance had been received from Robert Key and Frank Field.
  - (c) **Attendance Allowance:** The General Secretary reported that the attendance allowance case for which Counsel had been engaged had been successfully dealt with by the Social Security Commissioner. He also mentioned an important Commissioner's decision on Mobility Allowance for people with haemophilia which had been obtained. The Chairman expressed the congratulations of the Executive Committee to the General Secretary for having achieved those two matters which would be so important for future claims for both attendance allowance and mobility allowance for people with haemophilia and it was agreed that gratitude be recorded for those important achievements.

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- (d) Executive Conference: The Chairman reported that he and the General Secretary would be reviewing the content of the Executive Conference and stressed the importance of Working Parties checking their own positions against the minute of the meeting. The importance of individual Working Parties producing their own objectives was also stressed.
- (e) The Macfarlane Trust: The Chairman reported that the Macfarlane Trust was now a registered charity in its own right and that all the points recorded at 88.10 had been successfully dealt with apart from changing the name to "R G Macfarlane Trust". This had not been possible on account of the advanced stages reached with the enabling legislation based on the name "Macfarlane Trust". The Chairman also reported that the General Secretary was convening a meeting of the Trustees which, it was hoped, would take place before the end of March. The Chairman asked members of the Executive Committee with views on the criteria for allocation and disbursement of the Fund to communicate those to him, via the General Secretary, as soon as possible.

88.18

#### WORKING PARTY REPORTS

- (a) Finance and General Purposes: John Prothero reported that the Audit had now been completed and that there had been an excess of expenditure over income. It was hoped that a refund would be obtained for £2,500 corporation tax which had been paid over the last three years. The Executive Committee expressed their gratitude to Linda Matthews for the hard work and conscientious effort she had put into both achieving the audit and establishing the new computerised accounting system.
- (b) Blood Products/Treatment and Care: Papers from the Committee were tabled, recording discussions at the last two meetings. These included reference to the new era of Blood Products. At the suggestion of Clive Knight it was agreed that the Treatment and Care working party would investigate treatments available for AIDS and, if possible, produce a paper on this.
- (c) Case Committee: Dr Kuttner reported that the Case Committee had met in January and considered forty-two applications for Financial Assistance. Thirty-four grants had been made, totalling £10,915.95. Six applications had been deferred for more information and two were refused. In February the Committee considered twenty-six applications for assistance, nineteen grants having been made totalling £4,433. Three applications had been deferred for more information and four refused. It was noted that money granted in respect of HIV infection in people with haemophilia would be recoverable from the Macfarlane Trust in due course and that, to the end of February, the total amount recoverable was £17,939. George Kirman expressed concern that the Macfarlane Trust should maintain the same level of flexibility and fast response to emergency applications for grant aid as was the case with the Haemophilia Society. The Chairman undertook to pass this on to the Trustees.
- (d) Overseas: The Chairman reported that Dr Smit Sibinga had now formally reported on his visit to India in November 1987. Dr Smit Sibinga was greatly concerned about the situation in India and felt that it demanded concerted action by WHO, Red Cross and Red Crescent Societies, etc. The Chairman agreed to keep the Executive Committee informed about developments in the subcontinent.
- (e) Publications and External Relations: The Executive Committee accepted the report of the P&ER working party and discussed the content of the 'First Tuesday' programme transmitted on 1 March 1988. There was a mixed reaction to the programme and its content. Concern was expressed that apparently new 'policy' had been made on behalf of the Society which was contrary to that previously agreed and made public. It was agreed that no blame was apportionable to anyone for this, but it was felt that policy statements should be agreed well in advance and adhered to. In the case of the £10m fund from the Government it was agreed that the approach would remain that of accepting the grant as a start, rather than condemning it as insufficient as a matter of policy.



- (f) Seminar: It was noted that the Executive Committee would be able to meet in full session and in working parties during the Seminar in Liverpool and, accordingly, it would not be possible for Executive Committee members to participate in workshops. It was agreed that members of the Executive Committee should make themselves available to delegates as much as humanly possible during the Seminar, since this was their one, and in some cases only, opportunity of meeting and discussing matters with elected members of the Executive Committee. A memo to this effect was to be circulated immediately to all members of the Executive Committee.
- (g) Sales: Keith Colthorpe reported that he was actively following up Christmas cards, etc, for 1988.
- (h) Group Liaison: At this stage the Chairman welcomed into the meeting Alan Brookhouse who had come to stress the importance of a Management Training/Group Development Role following the Needs Identification exercise held on 3 October 1987. Mr Brookhouse presented the opportunities which could be presented by following such a course and members of the Executive Committee were able to ask questions and discuss the matter with him. It was agreed that estimates of likely costs involved should be obtained and submitted to a future meeting of the Executive Committee. When this item was over, Mr Fitton and Mr Kirman left the meeting, in the company of Mr Brookhouse, to travel home from London. Detailed discussion of this item was deferred until a future date. [NB This agenda item was dealt with after 88.18(i).]
- (i) Grant Applications: The Chairman reported on applications for grants as follows:-
- (a) Dr C R Hay, Liverpool: The Officers supported an application for a grant of £3,000 per annum for three years to look into immunodepression caused by factor VIII concentrate. That this application succeed was proposed by the Chairman and agreed nem com.
- (b) Dr M O'Doherty, St Thomas': This application for a grant of £10,000 for one year to fund work on haemophilia, AIDS and lung epithelial permeability was supported by the Officers. That the application succeed was proposed by Mr Colthorpe, seconded by Mr Kirman and agreed unanimously.
- (c) Dr P B A Kernoff, Royal Free: This application for a grant of £11,044 to fund the salary of an MLSO for work on carrier detection and prenatal diagnosis using gene probes was also recommended by the Officers. That the application succeed was proposed by George Kirman, seconded by John Prothero and agreed unanimously.
- (d) Dr E Tuddenham, MRC Clinical Research Centre: Dr Tuddenham had applied for a grant of £2,000 per annum for two years, plus equipment costs of £311.60 in the first year, to meet the costs of a project on factor XI purification and characterisation. That this application succeed was proposed by Dr Kuttner and seconded by Andy Cowe. This was agreed unanimously.
- (e) Dr L A Parapia, Bradford: The Chairman reported that for the past two years the Society had funded, on a year-by-year basis a psychological study of HIV positive patients at Bradford. An application had now been received for renewal for a third year of the study. The Officer's recommendation was that this application for renewal not succeed. That this be so was proposed by Keith Colthorpe, seconded by Terry Fitton and agreed unanimously.
- (f) Dr R Mibishan, King's College: Dr Mibishan had applied for a grant of some £16,500 per annum for two years in connection with work involving the analysis of the molecular basis of mutation in haemophilia A and its diagnostic applications. Enquiries should be made of Dr Mibishan to establish whether this project is distinguished from similar projects. That apart, the Committee felt that this was a large amount to devote to work which was, in any case, being undertaken elsewhere and it was proposed by Dr Kuttner, seconded by Mr Kirman, that this application not succeed. This was agreed unanimously.

The recommendations from the Executive Committee will be presented at the Council meeting on Saturday 16 April 1988.

88.19 **WORLD FEDERATION OF HEMOPHILIA:** The Chairman briefly mentioned the forthcoming Congress in Madrid.

88.20 **GENERAL SECRETARY'S REPORT**

- (a) Office Security: It was agreed that further consideration be given to the installation of an alarm system in the office in view of the sensitive information held about people at 123 Westminster Bridge Road and the overall value of furniture and equipment within the Society's headquarters. The General Secretary reported that he had obtained one estimate and undertook to obtain a further estimate.
- (b) 1988 AGM: The 1988 Annual General Meeting will be held on 11 June in the Midland Institute in Birmingham. It was agreed that Dr Kernoff should be approached regarding a lecture on "New Era Blood Products". The Chairman undertook to write to Dr Kernoff.
- (c) 1988 Haemophilia Centre Directors' Meeting: The General Secretary reported that this meeting would be held in Dublin and that Mr Milne and Mr Prothero would attend on behalf of the Haemophilia Society.
- (d) Storage Facilities: It was agreed that outside storage facilities be obtained by the Society, in order to release some useful office floor space for packaging and distribution, etc. Later in the meeting, based on information provided by the General Secretary, it was agreed that the matter should proceed.
- (e) Crusaid: The General Secretary reported that a letter had been received from Crusaid seeking the support of the Society in a combined fundraising effort on behalf of the AIDS ward at the Royal Free Hospital. It was recognised that this ward would be widely used by large numbers of people with haemophilia and it was decided in principle to combine with Crusaid in this exercise. The General Secretary was asked to communicate with Crusaid about this.
- (f) Prison Art Show: The General Secretary had received a communication from the father of a boy with haemophilia who is currently serving a prison sentence. The prisoners had expressed an interest in, and wished to arrange an art exhibition in aid of, the Haemophilia Society. One of the greatest problems was in the framing of the works of art before putting them on display. It was agreed that this should be discussed further with the prison authorities.

88.21 **ANY OTHER BUSINESS:** There was no other business.

88.22 **DATE AND PLACE OF NEXT MEETINGS:** After discussion it was agreed that the date of the May meeting be transferred to Monday 9 May at the usual time at 123 Westminster Bridge Road.

Approved as an accurate record of the proceedings

GRO-C: Alan Tanner

The Revd Alan Tanner (Chairman)

9 May 1988