

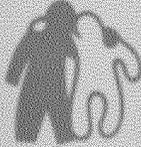
Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

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INFECTED BLOOD INQUIRY

WITN6392086



**The
Haemophilia
Society**

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

held on Thursday 8 September 1988, at
123 Westminster Bridge Road

Present: Rev Alan Tanner, Mr K Milne, Dr L Kuttner, Mr A Cowe, Mr T Fitton,
Mrs C Hazlewood, Mrs J Hodgson, Mr G Kirman and Mr J Miller.

AGENDA

- 88.45 Apologies for absence
- 88.46 Minutes of the meeting held on 14 July 1988
- 88.47 Matters arising
- 88.48 Reports from Working Parties
- 88.49 World Federation of Hemophilia
- 88.50 General Secretary's report
- 88.51 Any other business
- 88.52 Date and place of next meeting

88.45 **Apologies for absence** were received from John Prothero, Keith Colthorpe and Clive Knight.

88.46 Minutes of the meeting held on 14 July 1988, had been circulated in advance, and following a typographical correction at 88.39(c), final paragraph, third line, the word "argument", it was proposed by George Kirman, seconded by Andy Cowe, and agreed unanimously that the minutes be adopted as an accurate record of proceedings at that meeting.

88.47 **MATTERS ARISING**

(a) **Prison Art Show/Fundraising:** Julian Miller reported that he would be reviewing the paintings along with his contact, mentioned at 88.39(b), during September and would report further.

(b) **Factor VIII Supply:** This was dealt with it 88.48(b).

88.48 **REPORTS FROM WORKING PARTIES**

(a) **Finance and General Purposes**

(i) **Payment of Salaries:** The General Secretary reported that, following the discussion at the July meeting of the Executive Committee, further discussions had been held with Julian Miller and the Auditor, Matthew Dodson. As a result of those discussions it had been concluded that CentreFile offered the 'best deal' to the Society. Arrangements had therefore been made to proceed to set up this system with CentreFile under the terms agreed at 88.40(a).

(ii) **Cheque Signatories:** The General Secretary described how, under the previous Executive Committee, discussions had been held with the Auditor with regard to difficulties experienced in obtaining two signatories from members of the Executive Committee on each and every cheque.

Discussions had been held with Matthew Dodson whose recommendation was now available in writing. However, the General Secretary felt that there were matters which should be discussed within F&GP Working Party itself before making any final recommendation to the full Executive Committee.

- (iii) Fund-raising/Cash flow: The General Secretary drew the attention of the Executive Committee, once again, to the fact that fund-raising was proving difficult this year, not least because of the impression that the monies granted to the Society and administered by the Macfarlane Trust had, as it were, solved all the problems of people with haemophilia. The importance of fund-raising and support of fund-raising events was underlined.

It was agreed that a meeting of F&GP would be convened in the near future.

- (b) Treatment and Care: This working party submitted a detailed report of its activities covering questions of factor VIII supply in all parts of the United Kingdom and meetings held in that connection at the Blood Products Laboratory, Elstree, and with the Chief Medical Officer for Scotland. It was noted that Dr Harold Gunson had been appointed the first National Director of the National Blood Transfusion Service and it was hoped that this would lead to improved co-ordination of services by the thirteen regional centres. Congratulations had been expressed by the Society to Dr Gunson on his appointment. A meeting had also been held with the Medical Advisory Panel on the afternoon of 2 September 1988 at which, once again, the factor VIII supply question had been discussed along with questions arising from hepatitis B vaccine policy, monoclonally produced products, litigation and other issues of immediate interest and concern to people with haemophilia. It was becoming clear that there would be no major crisis arising from any shortage of factor VIII and while it was thought that local problems might emerge they would, by and large, have local solutions.

Ken Milne reported that the response to the Employment Survey had been disappointing but it was hoped to extract much useful information from it nonetheless.

The Treatment and Care Working Party had also met within the past few days and had discussed a possible conference on issues arising from HIV and AIDS in children and young people. The Executive Committee gave their support in principle to this idea and the General Secretary also mentioned the possibility of a two day national haemophilia conference in the autumn of 1989. Those ideas are to be explored further with other persons and parties likely to be interested in organising such a conference.

Andy Cowe voiced the appreciation of the Executive Committee to the Treatment and Care Working Party for all they had achieved during the summer months and especially in relation to setting up the meeting with the Medical Advisory Panel.

- (c) Case Committee Report: Dr Kuttner reported that in July fourteen grants had been made totalling £1,648. In August twenty-five applications had been considered and grants made totalling £3,555.80. The September meeting had considered only one application for financial assistance and had made one grant of £200. Dr Kuttner mentioned how the work of the Case Committee was much lighter now the Macfarlane Trust had started considering its own cases.
- (d) Overseas: The Chairman reported on the situation in India, mentioning problems being experienced by GRO-D and GRO-D and the helpfulness of Professor Pier Mannucci in Milan in dealing with those problems.
- (e) Publications and External Relations: Andy Cowe reported that he had received very little feedback during the summer on the new, draft, INTRODUCTION TO HAEMOPHILIA and to his audio-visual package. If comment was not forthcoming within the next few days, absence of comment would be assumed to indicate consent, and further steps would be taken towards the production of the items.

- (f) Group Liaison: Mr Kirman introduced the reports which had already been circulated. Mr Fitton reported on the excellent North East Group workshop held in Leeds and stressed how impressed he had been. It was noted that there was a proposal to hold a regional conference in the South West of England in spring 1989.

Mr Cowe was concerned that many problems relating to communication between the Society and Groups, and vice-versa, required urgent attention. It was therefore agreed, contrary to what happened in 1987, there would be a morning session at the November Council meeting which would be devoted to the Group Liaison Working Party. Their session would start at 11 am with coffee and continue until lunch at 1 pm on November 26.

- (g) Sales: In Keith Colthorpe's absence the General Secretary reported that the Christmas catalogue had been prepared and its circulation was currently subject to delay on account of the postal dispute. There was natural concern about the likely effects of a prolonged strike.

(h) Grant Applications:

(a) Dr R Mibashan, King's College Hospital: After further consideration and advice the Officers of the Executive Committee presented a majority recommendation that Dr Mibashan's application should not succeed. It was agreed that this would be the recommendation of the Executive Committee to the meeting of the Council to be held on 17 September.

(b) Dr D C Mitchell, Derbyshire Royal Infirmary: Dr Mitchell had applied for funding in the sum of £6,900 to support the work of a part-time HIV/AIDS counsellor. In presenting the recommendation of the Officers, the Chairman pointed out that a majority of the working party felt that this should fall to the Regional Health Authority for funding and, accordingly, recommended that the application not succeed. The Executive Committee agreed that this would be the recommendation to the meeting of Council on September 17.

(c) Dr Alison H Goodall, Royal Free Hospital: Dr Goodall had applied for funding for three years in the sum of £5,000 per annum. The funding was required for the purchase of monoclonal antibodies for a piece of research into immunological effects on multi-transfused people with haemophilia. It was recognised that similar work was being carried on at other Centres, but the importance of the work was recognised in the majority recommendation of the Officers that the application succeed for year one. It was agreed that this would be the recommendation of the Executive Committee to the Council when it meets on 17 September.

88.49 WORLD FEDERATION OF HEMOPHILIA: The Chairman reported that a large number of applications had been received for the newly created post of Executive Director of the World Federation of Hemophilia. Short listed candidates were due to be interviewed in the near future, the short listing panel being Charles Carman, President of the World Federation; Dr Shelby Dietrich and Dr Peter Levine, Medical Secretaries, and Alan Brownstein, Executive Director of the National Hemophilia Foundation. Concern was expressed that this was an over representation of North American opinion.

88.50 GENERAL SECRETARY'S REPORT: The General Secretary had circulated a written report in advance and he commented further on that report.

- (a) Staffing: It was noted that an additional member of staff had been employed, on a temporary basis, to assist with the transfer of records, etc, to the Macfarlane Trust. The full costs of this post would be borne by the Trust, in addition to repaying the Society for all the administrative costs involved to date. It was also noted that GRO-A would be leaving on 7 October 1988 as she was expecting a baby.

- (b) AIDS Co-ordinator: The General Secretary outlined Jonathan Cooper's employment and the fact that he had been paid over the past year with grants from International AIDS Day and Reader's Digest Association. It was unanimously agreed that Jonathan should be taken on to the main, core-funded, staff of the Society, and that his specific responsibilities should relate to HIV/AIDS issues, welfare rights and other areas of general assistance to the General Secretary. His future job title would be decided in conjunction with that of Linda Matthews, the Administrative Secretary.
- (c) Social Security Commissioners: The General Secretary outlined his dissatisfaction with two recent decisions from the Scottish Social Security Commissioner and he sought authority from the Executive Committee to take steps towards procuring Counsel's advice with regard to an appeal to the Court of Session in Edinburgh. The preliminary costs are likely to be in the region of £500. It was proposed by George Kirman, seconded by Andy Cowe, that this matter should proceed as far as obtaining Counsel's advice.
- (d) Local Group matter: The General Secretary had already circulated members of the Executive Committee with documentation which had emanated from a local Group, and been sent to a number of MPs, regarding the supply of factor VIII. Concern was expressed that the content could affect the credibility of the Society as a lobbying group since it contained inaccurate and erroneous material. It was agreed that those who had received this correspondence from the Group in question should be sent a copy of recent correspondence from Mrs Edwina Currie, Parliamentary Under Secretary of State for Health.
- (e) Medical Advisory Panel: It was agreed formally that Dr Christopher Ludlum should be co-opted to the Medical Advisory Panel and that his election to that body should be put to the 1989 Annual General Meeting.
- (f) The Right Honourable John Moore/The Right Honourable Tony Newton: The General Secretary reported that he had written to the gentlemen mentioned above on their new appointments. Each had replied in satisfactory terms.
- (g) The Aegis Group: The General Secretary reported that a member of Aegis Group had called at the office to discuss the possibility for achieving change in European Law, as it affects people with HIV and AIDS, through the European Commission. While the General Secretary felt that it was entirely appropriate for those steps to be taken, he doubted whether the Aegis Group was the appropriate body to do it. The matter was left to lie on the table.
- (h) Committee Room/Office space: It was accepted in principle that the Committee room was not serving a totally useful purpose and that consideration should be given to finding outside accommodation for Executive Committee meetings. This matter would be considered further over the coming months.
- (i) Annual Holiday Entitlement: After discussion it was agreed that the annual holiday entitlement of senior staff; David Watters, Jonathan Cooper and Linda Matthews, would be twenty-five days, and that all other staff would have their entitlement increased to twenty days.
- (j) Bereavement Project Booklet: The General Secretary outlined a draft publication that had been received from Newcastle, prepared under the guidance of Mrs GRO-D and her bereavement group. The Chairman had studied the draft and felt that it added little to the material already available on bereavement. As a result, he felt disinclined to recommend that it be funded by the Society. He was, however, prepared to discuss this with Mrs GRO-D directly. The Executive Committee agreed with his recommendation. Mrs Hodgson asked if she could see a copy of the draft and this was provided by the General Secretary.
- (k) Education Project: The General Secretary reported that a letter had now been sent to the DHSS along the lines of the draft Education Project submitted to the last meeting. No definitive reply had been forthcoming from the Department.

- 88.51 **ANY OTHER BUSINESS:** Amendments were made to the list of proposed dates for meetings in 1989 and the finalised list is attached to these minutes.
- 88.52 **DATE AND PLACE OF NEXT MEETING:** Thursday 10 November 1988 at 6 pm for 6.30 pm.

Approved as an accurate record of the proceeding of the meeting

GRO-C

Rev Alan Tanner (Chairman) 10 November 1988