

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392088



**The
Haemophilia
Society**

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

held on Tuesday 10 January 1989, at
123 Westminster Bridge Road, SE1

Present: Revd Alan Tanner, Mr K Colthorpe, Mr A Cowe, Mrs C Hazlewood, Mrs J Hodgson,
Mr G Kirman and Mr C Knight.
In attendance: Mr D Watters (General Secretary)

AGENDA

- 89.01 Apologies for absence
- 89.02 Minutes of the meeting held on 10 November 1988
- 89.03 Matters arising
- 89.04 Reports from Working Parties
- 89.05 World Federation of Hemophilia
- 89.06 General Secretary's Report
- 89.07 Any other business
- 89.08 Date and place of next meeting

89.01 **APOLOGIES FOR ABSENCE** were received from Dr L Kuttner, Mr K Milne,
Mr J Prothero, Mr T Fitton and Mr J Miller.

89.02 **MINUTES OF THE MEETING** held on 10 November 1988 had been circulated in
advance. Their adoption, as an accurate record of proceedings at that meeting,
was agreed unanimously, having been proposed by Keith Colthorpe and seconded by
George Kirman.

89.03 **MATTERS ARISING:**

- (a) **Education Working Party:** The General Secretary reported that invitations
to serve on this Working Party, to be chaired by Caroline Hazlewood, had been
sent to GRO-A and GRO-A who are parents of children with
haemophilia and also serving teachers. In addition, an invitation had been
extended to GRO-A, Chairman of the Birmingham Group. To date
GRO-A and GRO-A had accepted the invitation and no word had
been heard from GRO-A
- (b) **Birmingham AIDS Helpline:** No further information had been received on this
project.
- (c) **Prison Art Show:** In the absence of Julian Miller there was nothing further to
report.

REPORTS FROM WORKING PARTIES

- (a) Finance and General Purposes: A draft, provisional, budget for 1989 was tabled. This had not been to a full meeting of F&GP. Discussion took place about F&GP and its role in the work of the Society.
- (b) Treatment and Care: Caroline Hazlewood presented the report of the Treatment and Care Working Party. Particular discussion took place on the following topics:
- (a) Holistic Health: After a careful discussion it was agreed that the Society's position on Holistic Health was not that of recommending it, as such. It was rather an option which some people, but not all, might find helpful. It was recognised that there were a variety of methods and approaches to 'wholeness' and this was one option which was being watched with particular interest.
 - (b) MSC Employment Booklet: This is currently being revised and the Department of Employment had sought comments on that revision. It was agreed that members of the Executive Committee should feed comments to the Treatment and Care Working Party through the General Secretary.
 - (c) Sterilisation, Pregnancy and HIV: It was reported that two cases had come to light concerning women who had been sterilised (one following a termination of pregnancy) without being given proper and informed choice about the matter. Concern was expressed about this and it was agreed, as a matter of policy, that it was no longer the case that women should necessarily be advised to avoid pregnancy at all costs - in all cases, direct, personal, counselling should be given and the case discussed completely, enabling an informed decision to be made by the patient. It was agreed that this matter should be discussed further with the Medical Advisory Panel at their meeting in March.
 - (d) Genetics and Embryos: A discussion was held on ethical issues surrounding advances in genetics and embryonics. It was agreed that people with haemophilia should be given as much information as possible to enable them to make an informed choice.
 - (e) Meeting with Parliamentary Under Secretary: A brief report was given of the meeting with Mrs Edwina Currie and the useful assurance, obtained at that meeting, that cost would not be a limiting factor in the import of adequate supplies of factor VIII to meet the UK demand.
 - (f) Scottish Blood Transfusion Service: It was noted that attempts were being made to establish a dialogue with the senior staff in SBTS with a view to safe-guarding the Scottish supply situation.
- (c) Case Committee: The General Secretary reported that, at the December meeting of the Case Committee, grants totalling £816 had been made in respect of eight applications. One application had been deferred and two applications had been refused. Discussion took place on the low level of applications to the Case Committee and it was agreed that this matter should be referred back for fuller discussion by that Committee.
- (d) Overseas: The Chairman reported that he was travelling to India on 22 January along with Professor Mannucci, to hold a Workshop in New Delhi. In connection with continued assistance to people with haemophilia in India, it was agreed that there was a need for better communication and, more particularly, identification of a specific project by those responsible in India. The Chairman was asked to convey this message to them during his visit.
- (e) Publications and External Relations: Andy Cowe introduced the new publications produced since the last meeting - a new 'Membership Form' and 'What The Society Can Do For You' in a new format. The 'Update' Number One, 1989, had been dispatched, along with Membership Application Forms, on 9 January 1988 and the first edition of the 1989 Bulletin was nearing completion. It was anticipated that there would be a number of publications in this coming year from T&C Working Party.

Mr. Cowe
Mr Cowe also sought authority to proceed with production of 'The Children's Haemophilia Book' by Dick Bruno. This had been out of print for some time and it was agreed that £2,800 be made available for the production of 2,000

copies in conjunction with Speywood Laboratories and the Canadian Hemophilia Society who would make a similar contribution to the production costs. This was proposed by George Kirman, seconded by Keith Colthorpe and agreed unanimously.

Discussion also took place on the profile of HIV/AIDS-related matters in the Bulletin. It was agreed that the balance was just was about right and P&ER were invited to continue to use their discretion in this matter.

(f) Group Liaison/Training:

- (a) South Wales: A request for an HIV Seminar, held and funded locally, was discussed and agreed. This Group was also interested in the holistic approach and Jonathan Cooper had already been in contact with them about that.
- (b) New Groups: It was noted that the Scottish Group would subdivide into West of Scotland and Southeast of Scotland Groups and that the 'banns' had been called at the November meeting of the Council.
- (c) Southwest Regional Seminar: It was noted that this was in some jeopardy on account of a low uptake. Attempts were being made to stimulate awareness of the conference and its potential for people with haemophilia in the Southwest.
- (d) Newsletter: It was noted that Jane Hodgson would be producing a short Newsletter for Groups, following each meeting of the Executive: A dummy had been produced after the last meeting and the first edition would go out immediately following the January meeting.

- (g) Sales: Keith Colthorpe reported a profit of £4,417 from the sale of 1988 Christmas cards. In addition he reported sales of almost £1,118 of 1987 cards. The gross income from sales for 1988 was £11,394. Mr Colthorpe sought permission to repack the 32,200 cards held over as balance of stock into 'Bargain-packs' for sale throughout the year. Approval was given for this work to be carried out.

Mr Colthorpe also sought permission to spend £750 on flexible plastic keyrings, in the shape of the Haemophilia Society logo. These would cost approximately 30p each and retail at 50p. This was agreed.

- (h) Grant Applications: The General Secretary reported that four grant applications had been received: two from Glasgow, both relating to the immune system; one from the Royal Free Hospital on genetics and one from Cambridge in connection with improvements to the Centre there. These would be considered between now and the February meeting of the Executive Committee and, where possible, recommendations framed.

89.05 **WORLD FEDERATION OF HEMOPHILIA:** The Executive Committee expressed profound disappointment and disquiet that, after a lengthy period for advertising and selection of a new Executive Director of WFH, the person offered the post had not accepted it. The Chairman was asked to convey this feeling to the meeting of the Executive Committee of WFH, being held in London that week.

89.06 **GENERAL SECRETARY'S REPORT:** The General Secretary had tabled a report, the main points of which were as follows:

- (i) CERT: It was noted that Foster Murphy, of the Volunteer Bureau, had been appointed as our Assessor and that a preliminary meeting would be held with him on January 18. It was important that members of the Executive Committee fed their thoughts, to the small Committee who would meet him, through the General Secretary.
- (ii) Members' Records: It was agreed that there should be weeding of the records of those members no longer on the mailing list. This will be done sensitively and confidentially, using a shredder to destroy any records. It was noted that the records of Officers and former Officers of the Society should be retained. Clive Knight agreed to assist the General Secretary in determining a policy on this.

- (iii) International Airlines Charity Ball: It was confirmed that the Committee of the Airlines Charity Ball had given the Society the benefit of the Ball for the next three years. ~~Mr Kirman expressed dissatisfaction with the way the Ball had been publicised and tickets made available, in 1988.~~
- (iv) Scottish Social Security Commissioners' Decision: It was noted that, in the light of Counsel's Opinion, it had been decided not to proceed with a formal appeal to the Court of Appeal in Edinburgh. In the event neither Counsel, the Scottish Solicitors, nor our own Solicitors in London, will be making any charge for the work done. This is an effective saving of £700.
- (v) Staff: It was reported that Paul Burba had been appointed to replace Jean Chilemba as Audiotypist/Receptionist and that he had taken up his duties in early December.
- (vi) 1989 AGM: It was agreed to invite Dr Korn, pioneer of the North Wales Adventure Holiday, to give the afternoon lecture at the 1989 AGM. The General Secretary was asked to look for venues other than the Royal Free Hospital. Working Parties were also invited to submit material for the Annual Report.
- (vii) Staff Meetings: The General Secretary reported that weekly staff meetings were now held on Wednesday mornings. A number of issues had already emerged and those were reported for interest.
- (viii) Office Equipment: The General Secretary reported that he was investigating future equipment for the office, in particular network computerised systems. Approval for this course of action was proposed by George Kirman, seconded by Caroline Hazlewood and agreed unanimously.
- (ix) Water Charges: It was agreed that the office should switch to metered payments for water and sewerage charges. It was anticipated that this would bring about a substantial saving.
- (x) London Marathon: The General Secretary reported that Dr Mark Winter would run on behalf of the Society in the London Marathon on Sunday 23 April, 1989.
- (xi) West-European Haemophilia Meeting: The Dutch Haemophilia Society were co-ordinating a meeting of Western European Haemophilia Societies, to be held in Holland over the weekend April 7-9, 1989. An invitation had been extended to all Member Organisations to send a delegate to this conference which would discuss problems such as the supply of factor VIII, haemophilia and AIDS, as well as the implications of 1992 for the international exchange of coagulation factor products, etc. It was proposed by the Chairman and agreed unanimously that the General Secretary attend this meeting and that his expenses be met.
- (xii) 1989 Council Meeting Venues: The General Secretary announced that, apart from the Council and AGM on Saturday 27 May 1989, all other meetings would be held in the Hertford Suite at the Great Northern Hotel, Kings Cross.

Mr Kirman suggested that we should seek a different venue for meetings of the Executive Committee, since he felt that the Committee room at 123 Westminster Bridge Road was too small and did not afford the facility of a table around which all members could sit. The General Secretary was asked to explore this question further.

89.07 ANY OTHER BUSINESS

- (a) White Paper on Health Service: Andy Cowe asked that the General Secretary explore any implications of this White Paper to people with haemophilia and report to a future meeting of the Executive Committee.
- (b) Patient Comforts, Edinburgh: Andy Cowe sought permission from the Executive Committee for the expenditure of £600 on patient comforts at the newly established Edinburgh Centre. This was seconded by George Kirman, and agreed unanimously.

89.08 DATE AND PLACE OF NEXT MEETING: Thursday 9 February 1989 - venue to be announced.

APPROVED as an accurate record of the meeting: 9 February 1989

GRO-C

Rev'd Alan Tanner (Chairman)