

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392154**

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MINUTES OF A MEETING OF THE EXECUTIVE COMMITTEE  
HELD ON THURSDAY 25 MARCH 1993  
AT CHARITYBASE, 50 WESTMINSTER BRIDGE ROAD, LONDON SE1

Minute No

**Present:** The Rev Prebendary A J Tanner (Chairman), Mr K Milne, Mr A Cowe,  
Mr G Clarke, Mr R Dickason, Mr S Taylor, Professor L Evans, Mr J Lander.

**In attendance:** Mr D Watters (General Secretary), Mr G Barker (Deputy General Secretary),  
Ms S Archer (Resources Manager) and Ms R Benson (Minutes Secretary).

**AGENDA**

E93.11 Apologies for absence  
E93.12 Minutes of the meeting held on 4 February 1993  
E93.13 Matters arising

*Matters for discussion and decision*

E93.14 Staff/premises review  
E93.15 Authority, roles and responsibility  
E93.16 Fundraising group  
E93.17 The Editor and publications  
E93.18 Review of committees  
E93.19 Executive Committee Day agenda  
E93.20 Resources: adoption of audited accounts  
E93.21 Strategic Plan: Task Group 4  
E93.22 Member Services: use of assigned sponsorship monies  
E93.23 Member Services: policy on grants to members

*Matters for question and comment*

E93.24 European activity  
E93.25 General Secretary's Report  
25.01 Member Services Department report  
25.02 Resources Department report  
25.03 Policy and Development Department report  
25.04 Harrogate: follow-up actions  
25.05 Strategic Planning  
25.06 Fundraising

- E93.26 Macfarlane Trust
- E93.27 World Federation of Hemophilia
- E93.28 Consideration of presentation of papers
- E93.29 Any other business
- E93.30 Date and place of the next meeting

Pre-meeting papers had been circulated giving detailed reports on agenda items to be discussed.

#### E93.11 Apologies for absence

Apologies for absence were received from Mr Lawson, Mrs Hodgson, Mrs Guy and Mr Colthorpe.

#### E93.12 Minutes of the meeting held on 4 February 1993

The minutes of the meeting held on 4 February 1993 were amended at 04.1 (k) to read "... issues involved required further consideration by Mr Watters who at the Chairman's suggestion agreed to present a paper to the March meeting of the Executive Committee. In the meantime the Review Body was stood down." Accepting this clause the minutes were proposed as an accurate record of the proceedings by Mr Cowe, seconded by Mr Taylor, and agreed unanimously.

#### E93.13 Matters arising

There were no matters arising.

### *Matters for discussion and decision*

#### E93.14 Staff/premises review

**14.1 Premises review:** A paper on the options open to the Society in moving premises to 1 Kennington Road or remaining at 123 Westminster Bridge Road had been circulated. Mr Clarke said that the Society was being pressed by British Rail to sign the lease and in doing so it would have to pay £32,000 in back rent. The Society's solicitors advised that by not signing the Society would not be liable for this sum. Mr Clarke said that in moving to the other offices the Society would make a further saving of approximately £7,000 a year until 1996.

There was some discussion and the Committee **AGREED** that subject to legal reassurance on the payment of the back rent, and to Mr Taylor and Professor Evans visiting the new premises, the national office should move to 1 Kennington Road. This was proposed by Mr Clarke, seconded by Mr Milne, and **AGREED** unanimously.

**14.2 Staff review:** Mr Watters presented Mr Clarke's statement on the proposed staff review to the Committee for discussion.

*To Review structure and manpower in the light of the changing needs of the Haemophilia Society and the economic climate.*

1. *The study of current staffing should, inter alia, consider remuneration compared with other organisations on a function and reward basis and should establish the particular skills and expertise of the post-holders. In addition, the degree to which staff engage in urgent as opposed to priority matters and authorised as opposed to unauthorised work along with chains of command must be considered.*

2. *Thereafter the study should consider what skills and expertise will be needed in conducting the Society's affairs in the future.*
3. *Finally existing and required future staffing needs should be reconciled so that overlaps and shortfalls are identified and a proposal drawn up suggesting the means by which these can be addressed – eg training, additional staff, other staff, etc.*

Mr Clarke regretted that he was no longer able to undertake the review because of pressure of work. There was a brief discussion and Mr Dickason proposed Professor Evans who agreed to take on the task, saying that he would find it interesting and worthwhile.

It was **AGREED** that Professor Evans would prepare a proposal setting out his methodology and that this would be circulated before the next Executive Committee meeting to both staff and the Executive.

#### **E93.15 Authority, roles and responsibility**

It was agreed to discuss this issue under E93.19 Executive Committee Day Agenda.

#### **E93.16 Fundraising group**

The Chairman reported that the Fundraising Group (the Chairman, Professor Evans, Mr Clarke, Mr Taylor) had interviewed three shortlisted fundraising consultants and had been in complete agreement in choosing Chapter One. They had met Mr Anthony Clay, the person who would be responsible for the audit the company proposed to carry out for the Society, and he was, the Chairman felt, someone with whom the Society could establish a good rapport. The audit fee was £8,300 plus VAT and expenses and would take two months. It would include an examination of the possibility of employing an in-house fundraiser.

The Committee **AGREED** that after the audit Chapter One's services might be called upon occasionally as and when the need arose.

The Committee considered the Society's position with regard to McDonald and Associates. There was concern that various fundraising projects already started should be successfully concluded, not only in terms of funds raised, but also in terms of goodwill generated.

At the Chairman's suggestion it was **AGREED** that the Fundraising Group look at a possible interim replacement to manage these projects and also that legal advice be taken on an earlier termination of the Society's employment contract with McDonald and Associates.

#### **E93.17 The Editor and publications**

It was agreed to discuss this under E93.19 Executive Committee Day Agenda.

#### **E93.18 Review of Committees**

It was agreed to discuss this under E93.19 Executive Committee Day Agenda.

#### **E93.19 Executive Committee Day Agenda**

There was discussion on aspects of the internal organisation of the Society, including authority, roles and responsibilities, the position of the Editor and Society publications and Committee structures. The Committee felt these were important issues and that time should be devoted to them at the Executive Committee Day on 15 May 1993. It was also felt that a review of

Committees was of primary importance, and that the other issues would naturally follow on. Professor Evans suggested that the Chairmen of Committees, the Chairman, the Managers and other members of the Executive Committee who held views on the roles and responsibilities of the Society's committee structure should submit brief papers to Mr Barker, arriving no later than 19 April 1993.

The Committee **APPROVED** Professor Evans's proposal for pre-meeting papers and it was **AGREED** that Mr Barker would collate the papers.

Mr Taylor and Mr Milne raised dissenting voices that not enough time was given to consideration of topics such as recombinant products, high purity blood products and European matters.

The Committee **AGREED** that such issues should be part of a rolling programme, abstracted from the Policy Committee's schedule, for regular discussion at Executive Committee meetings.

It was proposed from the Chair and **AGREED** that for the meeting on 15 May an allocation of 1/2 hours be given for the review of Committees and one hour for discussion of a topic to be recommended by the Chairman, Mr Watters and Mr Barker.

**E93.20 Resources: adoption of audited accounts**

Mr Clarke reported that the Audited Accounts had been satisfactorily prepared and recommended their formal adoption to the Executive Committee; this was seconded by Mr Taylor, and **AGREED** unanimously.

**E93.21 Strategic Plan: Task Group 4**

Mr Barker reminded the Committee that at the last Executive Committee meeting [E93.04.1 (a)] it had been agreed that Task Group 4 be reconvened in order to develop and present proposals on membership development. It had been noted that it was important that changes to Council be presented carefully. The Committee was asked to consider the following proposals:-

- (a) That Task Group 4 be reconvened and asked to examine the roles of local Groups and Council with a view to developing proposals (which might require changes to the Memorandum and Articles of Association) to give all members the opportunity to participate in the consultation and decision making processes of the Society.
- (b) That Task Group 4 also be asked to look at ways of promoting membership of the Society and to consider the idea of different categories of membership.
- (c) That the membership of Task Group 4 be increased from the Chairman, Mrs Guy and Ms Archer to include Mr Dickason and Professor Evans.
- (d) That at a later date the membership be further increased to include one or two representatives from local Groups or Council.

This was proposed by Mr Cowe, seconded by Mr Milne, and **AGREED** unanimously.

**E93.22 Member Services: use of assigned sponsorship monies**

Mr Watters reported on, and sought clarification on the Society's position regarding assigned sponsorship. He reported on the following items:

Armour     £1,500 x4 [£6,000] for Haemophilia Days in 1993

£1,500 towards Chairman's Conference [Day]

£2,500 towards membership promotion with the prospect of additional funding if proposals are made.

BPL        £15,000 to fund costs of Bulletin in 1993  
The 'promise' of funding for an opinion formers newsletter  
UK Haemophilia Centre Directory - ?£3,000

Porton Products     £5,500 to fund costs of Update in 1993

Octapharma        £2,000 with no strings attached

Alpha UK and Immuno had the potential to provide funding and in addition £5,000 had been received from an international federation of plasma producers to enable the Society to be active in Europe in connection with the Ceci and Van Aken Reports. A further £5,000 would be available if necessary.

The Committee established that the group of plasma producers was a trade consortium with vested interests. It was felt that caution should be exercised in the way the Society accepted and made use of funds from commercial sources, while accepting Mr Taylor's point that the Society would not have been able to be influential in Europe had it not received sponsorship. Mr Clarke proposed that, when taking sponsorship, the Society adjust its budget accordingly and that the Executive Committee should approve expenditure beforehand. This was noted.

Mr Watters asked the Executive Committee to consider the matter of the proposed opinion formers' newsletter and it was agreed that sponsorship should not be sought, but that it should be an in house production. The allocation of monies received was **AGREED**.

#### **E93.23    Member Services: policy on grants to members**

Mr Milne recommended to the Executive Committee the following statement on grant making policy agreed by the Member Services Committee. This had been circulated to a number of health care professionals for comment, who, while welcoming the paper, had regretted the financial restraints that made such a document imperative.

**The Process:** An application must be made by a health care professional on the current pro-forma provided by the Society. Applications may be discussed in advance with the General Secretary although any decisions can only be made upon receipt of the final documentation.

Initial decisions on applications up to £500 are made by the General Secretary or designated staff. Generally speaking decisions can be made speedily: the issuing of a cheque may take up to seven days. Only in exceptional circumstances – such as difficulty in accessing cheques signatories – will this take longer. Health care professionals will be advised if such a delay is likely to occur in issuing cheques.

If staff do not feel able to approve a grant up to £500 an appeal can be requested and this will be considered by members of the relevant Committee of the Executive Committee. Reasons for refusal will not necessarily mean rejection of any application: staff may feel, for instance, that they lack guidance from the Committee on granting such applications, or they may seek clarification or more information.

All applications for amounts over £500 are automatically referred to members of the relevant Committee for their consideration.

**The Practice:** The Haemophilia Society has limited amounts of money available to assist individuals with problems arising from their haemophilia.

It should be noted that grants are only made for people with haemophilia and their family and for needs arising from haemophilia. There is no question of 'entitlement' and means will always be a relevant consideration in looking at individual applications.

While each application is dealt with on its merits the Society's policy is not to make a grant in respect of debts, and grants will not be paid retrospectively - ie, after expenditure has been incurred; with deposits on Motability motor cars, the purchase of motor cars or other transport costs. Deposits on telephones have posed problems, and the Society is not able to pay them in the ordinary course of events. Society funds cannot be used to 'prop-up' the National Health Service and, consequently, health care or items of medical equipment cannot be provided using Society funds. Household items such as washing machines will not normally come within the remit of the Society's grant making ability and claims are unlikely to succeed.

Where financial need exists assistance may be available to help with the installation of a telephone where there is a child with haemophilia or an adult who benefits from home therapy, only if assistance is not available from the local social services department under the Chronically Sick and Disabled Persons Act.

Where there are acute social or medical reasons the Society will consider helping people with haemophilia with holidays: this will not necessarily extend to all household or family members.

In exceptional circumstances individual cases of hardship, however they arise, will be considered quickly and sympathetically by the Society.

It must always be appreciated that the Society's funding is small by comparison with other grant making bodies [eg the Family Fund or the Macfarlane Trust] and consequently we cannot entertain large grant applications. Preference is always given to those applications which seek innovative responses to individual circumstances. Claimants must indicate whether applications have been made elsewhere and the result of such applications.

Mr Cowe took issue with the wording of the first sentence and asked that it read "An application must normally be made by a health care professional ...". He said that if a health care professional were to be obstructive, the insertion of "normally" would mean that the prospective applicant would not be excluded from approaching the Society. Mr Cowe commented, also, on the number of negatives contained in the paper and wondered whether the presentation might not be improved if the wording were to be switched to sound more positive.

With these two caveats the Committee unanimously **APPROVED** the Policy on Grants to Members, the matter having been proposed by Mr Milne, and seconded by Mr Dickason.

### *Matters for question and comment*

#### **E93.24 European activity**

The Committee noted the Society's recent activities in Europe, including the lobbying over the Ceci Report, effectively emasculating it. Mr Watters reported that the World Federation of Hemophilia was sponsoring a conference in Brussels on Friday April 23 at which he and Mr Taylor had been invited to participate. Visits had been made, again by Mr Watters and

Mr Taylor, to European Societies in France, Belgium and Denmark. A meeting had been held in London with the Irish Society and another was due with the German Society. Mr Watters reported that, in addition, he had been invited to visit the Portuguese Society on Saturday 17 April with a view to discussing compensation issues at a national meeting.

#### **E93.25 General Secretary's report**

Reports from the Member Services, Resources and Policy and Development Departments had been circulated beforehand, as had reports on Harrogate and associated follow-up action, Strategic Planning and Fundraising. The Committee noted these reports.

Mr Barker brought to the Committee's attention the fact that there had been a delay in obtaining staffing support through NESOT Training Group in conjunction with the Employment Action Programme [initial agenda item E93.25.5 (b) Staffing Support for Implementing the Strategic Plan].

#### **E93.26 Macfarlane Trust**

The Chairman reported on moves by the Department of Health to set up a Trust for people who had been infected with HIV through transfusions or tissue transfers. It had not been legally possible to link it with the Macfarlane Trust, so a separate body was to be formed before the end of the year, to be known as the Eileen Trust. There would be five Trustees, three of whom would be appointed by the Macfarlane Trust. The administration of the new Trust would be handled by the Macfarlane Trust.

#### **E93.27 World Federation of Hemophilia**

Mr Watters reported that he had been asked to serve on the psycho-social planning committee for the XXI Congress in Mexico City on 25-30 April 1994, and would be attending a meeting in that connection in Milan on Monday 19 April 1993.

#### **E93.28 Consideration of presentation of papers**

The Committee was asked to comment on the presentation of papers in advance of the meeting in which the issues connected with agenda items both for discussion/decision and question/comment were laid out in detail. The Committee expressed appreciation of the new measures.

#### **E93.29 Any Other Business**

Mr Watters raised the following items:

**29.1 Society Awards:** Mr Watters asked that a formal process for examining and deciding upon Society Awards be agreed. Upon the proposal of the Chairman it was **AGREED** that this continue to be carried out by the Chairman and Mr Watters.

**29.2 Executive Conference and Annual Service of Thanksgiving:** Mr Watters proposed that, as the Executive Conference was to be non-residential and held in London over the weekend of 30/31 October 1993, in order to save the Society's funds the Annual Service of Thanksgiving be held at 3.00 pm on Saturday 30 October. The Conference could break for the Service, resuming again later in the day. Those who had to travel a distance could stay in a hotel, and costs be kept down. The Committee **AGREED** this proposal.



**29.3 Italian Adventure Holiday:** The Society had received a late request from Dr Peter Jones for approximately £2,000 to fund eight return air fares for an adventure holiday in Italy. There was a short discussion and it was **AGREED** to limit the grant to £1,000.

**29.4 Annual Candlelight Memorial Service:** An application for £100 had been received from the organisers towards the Annual Candlelight Memorial Service to be held on 23 May 1993 for those who had died of HIV. The Committee **APPROVED** this request.

**E93.30 Date and place of next meeting**

The next meeting of the Executive Committee will take place on Saturday 15 May 1993 at 10.00 for 10.15 am at Charitybase.

AJT/DW/RB 08.04.93