

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

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INFECTED BLOOD INQUIRY

WITN6392177



**MINUTES OF A MEETING OF THE EXECUTIVE COMMITTEE
HELD ON THURSDAY 4 FEBRUARY 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 Dickson, Mr S Taylor, Mrs N Guy, Mrs J Hodgson and 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

- E93.01 Apologies for absence
- E93.02 Minutes of the meeting held on 12 November 1992
- E93.03 Matters arising
- E93.04 General Secretary's Report
- E93.05 Macfarlane Trust
- E93.06 World Federation of Hemophilia
- E93.07 Grants Committee
- E93.08 Presentation of papers
- E93.09 Any other business
- E93.10 Date and place of the next meeting

E93.01 Apologies for absence

Apologies for absence were received from Mr Lawson, Professor Evans and Mr Colthorpe.

E93.02 Minutes of the meeting held on 12 November 1992

The minutes of the meeting held on 12 November 1992 were proposed as an accurate record of the proceedings by Mrs Hodgson, seconded by Mrs Guy, and agreed unanimously.

E93.03 Matters arising

There were no matters arising.

A report by the General Secretary, Mr Watters, had been circulated.

04.1 Harrogate Conference

Mr Watters said that at the Harrogate Conference a number of items had been dealt with and concluded, but there were other matters to be either reported upon, or discussed.

- (a) **Council agenda:** The Chairman observed that the last Council meeting held in November 1992 had not been as successful as it might have been, substituting as it had for the Chairman's Conference. He suggested that Council meetings should be primarily consultative procedures, with everyone being made to feel a part of the Society's plans and activities. There was general agreement with this view.

(i) **Presentation on implementing the Strategic Plan:** It was agreed that a presentation on the implementation of the Strategic Plan take place at the meeting, involving members of local Groups. Workshops would also be organised.

(ii) **Lecture on aspect of haemophilia care:** It was agreed that a lecture be given at the meeting on an aspect of haemophilia care.

Mr Dickason felt that changes to the structure of the Council agenda should be considered carefully, and an overall, long-term view of Council meetings taken, since members might become disaffected if changes were made on an ad hoc basis. The Committee noted Mr Dickason's views and asked that Task Group Four reconvene to consider these issues.

- (b) **Member Services Staffing:** The Committee noted that the staffing of the Member Services Department had reached a resolution, with Mr Watters and Mr Barker sharing the workload between them.
- (c) **Fundraising Task Group:** The Committee noted the re-drafted tender for a Fundraising Consultant, prepared by the Fundraising Task Group. The matter would be subject to report at the next meeting Executive Committee on 25 March 1993.
- (d) **Appointment of Fundraiser:** The Committee noted that the appointment was subject to the outcome of the tendering process, and it was agreed that the matter become the responsibility of the Fundraising Task Group.
- (e) **Fundraising plan 1993/94:** The Committee noted that the 1993/94 Fundraising Plan was dependent upon answers regarding the fundraising budget and responsibility for this would lie with the Fundraising Task Group.
- (f) **Roles/responsibilities/authority:** The Committee noted that a report by Professor Evans and Mr Barker would be presented at the next Executive Committee meeting on 25 March 1993.
- (g) **Responsibilities of Trustees:** After a short discussion in which the Chairman reminded Committee members of the importance of knowing the responsibilities incumbent upon being a Trustee, it was agreed to accept Professor Evans' proposal for Trustee training at the May Executive Committee meeting. The Committee requested preparatory papers and a 45 minute training session, including time for questions.

financial responsibilities: The Committee noted that a paper to be prepared by Mr Clarke, Ms Archer and Mr Watters would be considered by the Resources Committee for subsequent presentation to the Executive Committee at its March meeting.

- (i) **Editor and publications:** The Committee noted that the Editor, Mr Cowe, would report to the March meeting of the Executive Committee on roles and responsibilities in connection with the Society's publications.
- (j) **Executive Committee/Staff travel:** The Committee noted that the Resources Manager would prepare a paper for consideration by the Resources Committee on Executive/staff travel; a presentation would subsequently be made to the Executive Committee at its next meeting.
- (k) **Review Body: Staff and premises:** The Chairman reported that the Review Body had met on 19 January 1992 and made a proposal that involved the formal interviewing of staff by a member of the Executive Committee. The Chairman reported further that, after due consideration, Mr Watters had found this method of operation unacceptable. Discussion followed during which it became clear that the issues involved required re-consideration in relation to the overall objective. The Chairman suggested the Mr Watters present a paper at the March Executive Committee meeting on the objectives of the staff/premises review. This was agreed.
- (l) **Monitoring of Strategic Plan and planning process:** The Committee noted that the monitoring of the Strategic Plan and planning process was being carried out by Professor Evans, Mr Dickason, Mr Taylor and Mr Milne with Mr Barker, and would be reported upon at six-monthly intervals, the first report being due on 15 May 1993.
- (m) **Review of Committees:** Mr Watters reported that having discussed the review of Committees with relevant members of the staff team, it was thought that this might be better dealt with in parallel with the staff and premises review.
- (n) **Staff/Executive Committee expectations:** The Committee noted that an interim report on Staff/Executive Committee expectations was due on 15 May 1993 with a final report on 29 July 1993.
- (o) **Annual Budget 1994:** The Committee noted that the timetable for producing the 1994 Annual Budget would be a repeat of the schedule for the 1993 budget.

Finally it was noted that Mr Barker would be responsible for day to day monitoring and progress chasing of all Harrogate items.

04.2 Strategic Planning Report

An annexed Strategic Planning Report had been circulated previously and the Chairman asked for any comment. There was none, and the Report was noted.

04.3 Resources Department Report

A Report from the Resources Department had been circulated. The Committee considered the following items:

- (a) **Rent payments on 123 Westminster Bridge Road:** Ms Archer reported that the Society had agreed to the £20,000 annual rent including VAT. The Society owed BR £33,123 in total. The Committee considered how best to pay this back and agreed that it should be done as slowly as possible in agreement with British Rail.
- (b) **Computers:** Mr Watters reported that Digital had offered the Society a new computer system, subject to the 1992 accounts. Ms Archer had been instrumental in achieving this for the Society and the Committee thanked her warmly.
- (c) **Centralised banking:** Mr Watters reported that only a small number of local Groups was not yet in centralised banking, several Groups having recently joined the system. He added that the Member Services Committee had, at its latest meeting, recommended that it be made compulsory for all Groups to do so by the end of June 1993. This was agreed.

04.4 Member Services Department Report

The Member Services Department had circulated a report. The following matter was discussed:

- (a) **Publications:** Mr Watters reported that it was felt that BPL would be willing to sponsor *The Bulletin* with £15,000, and that Porton Products had indicated that it might be able to provide £5,500 for the production and mailing of *Update* three times a year.

After a short discussion the Committee accepted the Member Services' recommendation that the Society publish annually three *Bulletins* and three *Updates*, with the new budget monies used to produce an in-house document for opinion formers twice a year. BPL had indicated a willingness to consider this.

Mr Cowe said that he felt the inclusion of latest medical information in *The Bulletin* was valuable and appreciated by readers, and should not be cut out of the magazine. Mr Dickason said that any medical articles included ought to be written in language that would be intelligible to the layman, and that this should be clearly specified when commissioning pieces. He said also that the Society should let the readership know that the objective of *The Bulletin* was to be changed, and that its format should be altered to correspond with the new thinking. There was general agreement that clarity for the ordinary Society member was an over-riding consideration for all Society publications.

04.5 Policy and Development Department Report

The Policy and Development Department's Report had been circulated. The following items were considered:

- (a) **St Thomas':** Mr Barker reported that the Society had hoped that the press would cover St Thomas' difficulties over getting the District Health Authorities to pay for treatment provided by the Centre, but this had not materialised. The Hospital had written to DHAs, some of whom had agreed to pay, while others had said they would be contacting Regional Health Authorities. The Committee would monitor the situation.
- (b) **Blood products:** Mr Barker reported that the Policy Committee recommended that the Society's position on the availability of high purity products for all should be one of a gradual push to achieve this goal. It recommended also that the policy on treatment for children should be that prophylaxis was in general more important than high purity, and that it was undesirable for anyone to have to go back onto a less pure product. The Committee agreed both these policies.

- (c) **Van Aken Report:** Mr Taylor reported that events had moved quickly and a report by Mme Ceci for the Committee on European Public Health and Consumer Protection had, to a large extent, supported the Van Aken Report's theses on self-sufficiency within the European Community. Mr Taylor said that this report had arrived within the past few hours, and draft amendments had to be in by 9 February 1993. Mr Watters, Mr Barker and Mr Taylor were working at a suitable response and the Committee would be kept informed.
- (d) **Policy on Confidentiality:** The Policy and Development Committee recommended to the Executive Committee that the Society should have a statement on the confidentiality of information held by the Society about its members. This should include the precepts that no information about who was a member or any details about a member be released to any person or agency without that member's prior consent; that members have access to any information in their files within a given period of having made the request. It was also recommended that this policy not be publicised, but used when required.

The Committee approved the Policy and Development Committee's recommendations.

04.6 Medical Advisory Panel

The Chairman reported that a vacancy existed on the Medical Advisory Panel due to the death of Professor Arthur Bloom. Dr Christine Lee of the Royal Free Hospital had been suggested as a possible replacement. The Committee accepted Dr Lee's candidacy; her name was proposed by Mrs Guy, seconded by Mr Cowe, and there was unanimous agreement that the proposal be put before Council at its next meeting.

04.7 European Haemophilia Consortium

The Chairman asked the Committee for confirmation of the following clarification of the different roles played by Society staff and members of the European Haemophilia Consortium. The UK Society held the Secretariat of the EHC and in practice the work was done by Mr Watters and Mr Barker. The position of the National Member Organization was being represented, increasingly, by Mr Cowe and Mr Taylor.

The Committee agreed the above as the current arrangement of roles in connection with the EHC.

E93.05 Macfarlane Trust

05.1 Appointment of Trustees

The Chairman reported that the periods of office of the Macfarlane Trust's two medical Trustees, Dr E Mayne and Sister C Harrington, were both coming to an end. These two appointments were made by the Secretary of State at the recommendation of the Society, and were for two years' duration. It was recommended that Dr Mayne and Sister Harrington be asked to continue for another term.

The Committee approved this recommendation.

The Chairman recommended that the remaining six incumbents of Trustee positions within the gift of the Society might be asked, where appropriate, whether they wished to continue, or perhaps to rotate positions.

The Committee approved this recommendation.

05.2 Chairman's Report

The Chairman reported on an overture made to the Macfarlane Trust by the Department of Health that the Trust accept into its administrative system the care of those who had been infected with HIV through transplants or transfusions. The Trust had distanced itself previously from this group, while expressing sympathy, in order to maintain the special case status of haemophilia. However, it was now felt that the need to keep this separate status was no longer as pressing. Other countries, notably Australia and Canada, had included transplant/transfusion cases with those with haemophilia. There were about 100 such cases in the UK. The Chairman said that an additional Trustee with knowledge of transplants could be appointed to the Trust. There was a short discussion and it was agreed that the Trust's position would be improved if it were seen to be helpful in this instance. Mr Taylor said that he felt that the Society could hardly be anything other than supportive and sympathetic to this group; that they should have access to the Trust's support system, and that they should be welcomed.

The Committee agreed unanimously to recommend acceptance of the transfusion/transplant group under the umbrella of the Macfarlane Trust.

E93.06 World Federation of Hemophilia

06.1 Conference on European self-sufficiency

Mr Watters reported that the WFH was sponsoring a programme on European self-sufficiency in April, through the auspices of the EHC. Mr Taylor, as a consumer, had been asked to give a paper, and Mr Watters had been invited to act as a Commentor.

06.2 Decade Plan

Mr Watters reported that work on the Decade Plan progressed, with a number of people in the UK involved.

06.3 WFH logo

WFH papers had been circulated offering alternatives to the WFH logo which was to be changed.

The Committee agreed that Mr Taylor should be asked to formulate the Society's response.

E93.07 Grants Committee

Mr Watters reported on the following grant applications:

07.1 University of Bristol, Department of Orthopaedic Surgery

The Department of Orthopaedic Surgery at the University of Bristol had earlier applied unsuccessfully to the Society for renewal of a grant for the appointment of a part-time physiotherapist. This had subsequently been provided by the University. The Department had approached the Society again for £1,000 to enable the physiotherapist to write up her research. The Grants Committee did not recommend that this request be granted.

07.2 Lincoln Group

The Lincoln Group requested a donation of £1,450 towards the cost of platelet-counting equipment to be used at Lincoln County Hospital. The total cost of the equipment was £15,000. The Grants Committee recommended that the application succeed. The Executive agreed with this

view.

The Executive Committee endorsed the recommendations of the Grants Committee.

E93.08 Presentation of Papers

The Committee was asked to comment on the presentation of the meeting's papers. It was agreed that a separate agenda listing all reports and annexed sheets was useful, but that the separation of action sheets from the main body of reports was confusing. It was requested that cross-referencing of papers be thorough. The Committee requested also that the various categories of discussion/decision, question/comment and information/report be spelled out at the beginning of each item in the reports, rather than marking the texts with different print-types.

It was agreed that a revised format would be presented at the next Executive meeting.

E93.09 Any Other Business

There was no further business.

E93.10 Date and place of next meeting

The next meeting of the Executive Committee has been re-arranged to take place on Thursday 25 March 1993 at 5.30 for 6.00 pm at Charitybase.

AJT/RB 06.02.93