

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

WITN6392183



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MINUTES OF A MEETING OF THE EXECUTIVE COMMITTEE
HELD ON THURSDAY 6 JUNE 1991 AT 6.30 PM
AT HOTEL IBIS, 3 CARDINGTON STREET, EUSTON NW1 2LW

Minute No

Present: The Rev Prebendary A J Tanner (Chairman), Mr A Cowe, Mr K Milne, Mr N Lawson, Mr J Lander, Mr R Dickason, Mrs C Hazlewood, Mr K Colthorpe and Mr S Taylor.

In attendance: Mr D Watters (General Secretary), Ms L Matthews (Resources Manager), Mr G Barker (Policy Manager), Ms H Maynard (Member Services Manager) and Ms R Benson (Minutes Secretary).

AGENDA

- E91.13 Apologies for absence
- E91.14 Minutes of the meeting held on 7 October 1990
- E91.15 Matters arising
- E91.16 Report back from Residential Council
- E91.17 NHS Review
- E91.18 Reports from Committees
- E91.19 Follow-up to Horsted Place
- E91.20 General Secretary's Report
- E91.21 World Federation of Hemophilia
- E91.22 Any other business
- E91.23 Date, time and place of next meeting

E91.13 Apologies for absence

Apologies for absence were received from Mr J Miller and Mrs J Hodgson.

E91.14 Minutes of the meeting held on 28 February 1991

14.1 A correction to the title of the minutes should have read "28 February 1991", not "28 February 1990".

14.2 The headline at minute E91.02 should have read "Minutes of Executive Committee Meeting held on 4 December 1990" not "4 December 1991".

The correction of the minutes as an accurate record of proceedings was then proposed by Mr Milne, seconded by Mr Colthorpe, and agreed unanimously.

E91.15 **Welcome and new members**

The Chairman warmly welcomed Mr Taylor back to the Executive Committee. The Chairman also said that Mr **GRO-A** would be joining the Executive Committee at the next meeting.

Mr Milne congratulated the Chairman on his consummate and entertaining performance at the Annual General Meeting on Saturday 1 June 1991, and the Chairman in turn expressed gratitude and praise to Mr Watters for all his work, both before and during the meeting.

E91.16 **Membership of Committees**

The Chairman raised the matter of Committee membership, and said that if anyone was thinking of seeking a change in his or her place on a particular Committee they should let him know and this could be considered.

Mr Milne reported that Mr Watters had approached Mrs Norma Guy, Chairperson of the North West Group about the possibility of being co-opted to the Executive Committee, and she had agreed. There was unanimous approval of this idea.

E91.17 **Report back from Executive Committee Day**

Mr Cowe said that the day been a useful exercise in enabling members of the Executive to to realise more fully their potential, and the Chairman declared that it had provided an opportunity to meet in a relaxed way and get to know one another better. Mr Watters felt that as a result people should feel more secure about talking to one another, and that indeed, a greater communication between Committees as well as between the Executive and Committees would be good. Mr Colthorpe said that he would have appreciated the circulation of a written summary of the meeting to recap on the main points, and this was noted. Mr Watters said that the Committee should think perhaps of taking the process further at the next Executive Committee Residential meeting during the weekend of 4 - 6 October 1991. He suggested that the Society's strategic planning for the future be on the agenda for consideration. There was some discussion and concern was expressed that rather too much theorising might result, but Mr Taylor said that while it was important that the Society maintain an active profile, it was also necessary to keep in focus the manner in which things were done. There was general agreement that a small Project Team be set up, consisting of Mr Cowe, Mr Watters and Mr Dickason. The team would plan the October Residential Conference in consultation with the Chairman.

18.1 Member Services

- i) **National Feature and Thanksgiving Service:** Mr Milne reported that the Member Services Committee had not managed to come to a decision over the matter, and he asked for opinions from the Executive Committee. The Chairman thought that a national feature would be much appreciated by people who had lost those close to them, and that if it were fixed in a particular location people would travel from afar to visit it. The Committee agreed that Member Services should proceed with enquiries.

The Chairman announced that dates for the Thanksgiving Service were being considered, either in October or November, but the choice depended on the availability of the Phoenix Singers. Saturday 2 November, All Souls' Day, was most favoured.

- ii) **Groups:** Mr Dickason reported that a particular Group had been given a year to organize its financial affairs according to the Society's guidelines. He raised the broader issue of what was to be done if a Group continued to operate outside these guidelines; what constraints should the Society insist upon, and how, if it came to it, should a Group be wound up? The Committee agreed that this matter warranted further consideration in the interests of the Society as a whole.
- iii) **Medical Advisory Panel:** Mr Milne reported that a Project Team consisting of himself, Mr Cowe and Mr Barker had met to discuss the future of MAP, and Mr Barker had summarized the findings in a paper, which had been presented to both the Policy and Member Services Committees. Both Committees had felt that it was useful to have this regular forum, the Society being constitutionally obliged to have a MAP. However, there had been disagreement on whether the structure of the Panel should be broadened to include, for example, social workers, nurses and physiotherapists, or whether it should remain composed only of doctors. It was apparent, also, that the Society needed to define the function of the Panel, and to make clear what it expected of the Panel. For instance, members might be requested to speak on specific topics at seminars, or provide papers for Society publications. After some discussion the Committee agreed that Mr Watters would approach Dr E Mayne and other members of the MAP for their opinions on the matter. The Project Team was thanked for its work, and disbanded.
- iv) **Member Services Manager:** Mr Milne raised the issue of Mrs Maynard's workload, saying that at present 75 - 80% of her time was taken up with individual members' problems, and he wished this to go on record as the Resources Committee might be asked at a later date to approve an extra staff member. Mr Watters was currently doing the fostering of Groups, and if the Society's activities were to expand further into areas such as hepatitis, the Member Services Committee would not want to have to cut down on help offered to Society members. Mr Watters said that staff numbers and office space were matters for review by the Resources Committee.
- v) **Any other matters:** Mr Watters reported that arrangements for the One-Day Conference at Huddersfield were proceeding smoothly, and forty six delegates would be attending, with the addition of nine children. The programme had been amended to make way for a free period, providing a valuable interlude during which people could exchange views and experiences. Should members of the Committee wish to attend, they were asked to let Mr Watters know within the next ten days.

18.2 Resources

- i) **Fundraising Committee and McDonald and Associates:** The Chairman reported that Mr David Miller, Chairman of the Fundraising Committee had met with Mr McDonald to discuss areas in which the Committee was to become involved. Mr Miller was an excellent man for the job, with many contacts, and large, long-term goals would be sought, quite different to the shorter-term fundraising the Society did in association with Groups.

It was noted that the emergence of Trust hospitals could lead to competition for funding.

- ii) **Time off in lieu – proposal for Managers:** A paper had been circulated in advance and Mr Lawson said that this represented the end of a negotiating process that put right certain imbalances in working methods. New staff would have to accept that there would be times when they would be expected to work unsocial hours. There was a brief discussion, and the detailed proposition was agreed.

18.3 Policy

- i) **Editorial Board:** Mr Cowe raised the subject of the editing of publications. While a proposal for an Editorial Board had been agreed in the Policy Committee, and Mr Cowe himself had originated it, he now had reservations about the arrangement, and recommended reverting to the original system. There was some discussion, and Mr Cowe suggested that, in his editorial capacity, he work with Mr Watters on a general level, and with individual Senior Managers when a publication fell into their particular arena. This was agreed.

- ii) **National Health Service Review:** Mr Barker reported that he had met GJW and Health Network to discuss the entry of the NHS Review into the political and public arena. It was generally felt that a circumspect approach should be adopted.

A paper on standards of care would be produced, including a section on how the service would be delivered, and Drs Ludlam and Winter had agreed to comment on medical aspects of the document. Mr Taylor's advice that the Society should not make assumptions regarding the right of people with haemophilia to treatment was felt to be sound, and it was thought that the issue, an old one in the Society's history, was worth resurrecting. Mr Taylor said that the Society should be alert to the need to defend at all times the ground which it had won.

- iii) **Publications:** Mr Cowe said that there was nothing new to report.

- iv) **World Federation of Hemophilia Project Team:** Mr Taylor had circulated a discussion paper, the two main points of which being the perceived conflict between the WFH's representation of carers or consumers, and secondly the confusion over its supportive role versus leadership. Mr Taylor felt that there was a problem of identity, and that the Federation was unsure of its function. However, there had been a useful exchange with Mr Declan Murphy, and the Project Team would report further in due course.

- v) **Europe:** Mr Barker reported that he had attended a meeting of Euro-Citizen-Action-Service in Brussels on 24 May 1991, to discuss the establishment of a European Public Health Allowance. This had been valuable and there was a wide range of issues in which the Society could have an interest. Another meeting was due to be held in September, and the Committee approved unanimously the Society's continuing liaison with ECAS.
 - vi) **Whole Blood Transfusion HIV:** Mr Cowe reported that, following the appearance of this subject in the press, the Society, having been called upon for a statement, had declared sympathy for those people involved, at the same time maintaining the uniqueness of the Society's case and the fact that it was able to act only on the behalf of people with haemophilia.
- Mr Watters announced that he had been invited to speak at an All Party Parliamentary Group on AIDS and circulated notes he was intending to use relating the experience of the Society.
- vii) **Any other matters:** Mr Barker reported that the UK Declaration of the Rights of People with HIV and AIDS was due to be launched at Church House on 27 August 1991.

E91.19

General Secretary's Report

- 19.1 **US immigration:** Mr Watters reported that the changes due to be brought into existence on 1 June 1991 had been set back for sixty days for public consultation. In the meantime those who were HIV positive would have to apply for a waiver previously. It was suggested that Health Network might be asked to bear this development in mind for press coverage at the appropriate moment. This could be done in collaboration with the Terence Higgins Trust. It was to be blazoned in the July issue of *Update*.
- 19.2 **Haemophilia Centre at St Thomas':** Mr Watters said that there was to be a gathering to celebrate the installation of facilities for the treatment of haemophilia at St Thomas' on 16 July 1991 at 6.00 pm. This had been possible through the generosity of the family, friends and colleagues of the late Mr John Prothero. His family were enthusiastic that members of the Executive Committee might attend.
- 19.3 **Membership forms:** Mr Watters reported that plans for a new membership application form were being considered. It was being suggested that the forms be in two parts - a detailed version for new members, and a briefer variant for those subsequently re-joining the Society. Mr Watters said he would welcome suggestions after a draft form had been circulated.
- 19.4 **European Haemophilia Consortium:** Mr Cowe proposed, and Mr Colthorpe seconded that the European Haemophilia Consortium meet in Prague later in the year. This was agreed unanimously.
- 19.5 **Czechoslovakian Haemophilia Societies:** Mr Colthorpe proposed and Mr Lawson seconded that a total of £2,500 should be made available to the two state Haemophilia Societies in Czechoslovakia. This was agreed unanimously.

19.6 BPL: The Committee noted recent developments at BPL and their implications for haemophilia treatment and care.

19.7 Regionalization of Groups: It was agreed that the principles involved in the regionalization of Groups be examined by the Member Services Committee, and that a report should be presented to the Executive Committee at its meeting on Thursday 14 November 1991.

E91.20 World Federation of Hemophilia

Mr Taylor was to attend the International AIDS Conference in Florence, at which, for the first time, there was to be a session on haemophilia, arranged by WFH and to be chaired by Mr Murphy.

E91.21 The Macfarlane Trust

The Chairman reported that the machinery for dealing with the latest settlement was in action and the Macfarlane Trust had issued 709 cheques, of which 119 were in category G (those people affected by stress). Therefore, 590 people with HIV had been paid in full.

Mr Cowe suggested that another meeting with the Trustees might be useful and the Chairman agreed to propose this to the Macfarlane Trust.

The Committee was reminded that there was still a vacant Trustee position, and members were asked to give the matter their consideration.

E91.22 Any Other Business

There was none.

E91.23 Date of next meetings

The next meeting of the Executive Committee will take place during the weekend of Friday 4 to Sunday 6 October 1991 at the Doncaster Swallow Hotel.

Approved as an accurate record of the meeting

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[Signature Box]
.....
GRO-C

..... The Rev Prebendary A J Tanner
Chairman

DW/RB 26.06.91