

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

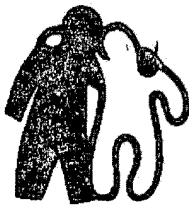
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**INFECTED BLOOD INQUIRY**

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**WITN6392181**

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MINUTES OF A MEETING OF THE EXECUTIVE COMMITTEE  
HELD ON THURSDAY 28 FEBRUARY 1991 AT 6.00 PM  
AT HOTEL IBIS, CARDINGTON STREET, LONDON NW1

Minute No

**Present:** The Revd Alan Tanner (Chairman), Mr K Milne, Mr J Lander,  
Mr R Dickason, Mrs C Hazlewood, Mrs J Hodgson and Mr N Lawson.

**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**

- E91.01 Apologies for absence
- E91.02 Minutes of the meeting held on 7 October 1990
- E91.03 Matters arising
- E91.04 Report back from Residential Council
- E91.05 NHS Review
- E91.06 Reports from Committees
- E91.07 Follow-up to Horsted Place
- E91.08 General Secretary's Report
- E91.09 World Federation of Hemophilia
- E91.10 The Macfarlane Trust
- E91.11 Any other business
- E91.12 Date, time and place of next meeting

The Chairman opened the meeting by paying tribute to [GRO-A] and [GRO-A] who had both died since the last meeting. He thanked members of the Committee who had attended the memorial service for [GRO-A] earlier in the day. It was felt that it had been a significant occasion for family and friends. Mr [GRO-A]'s particular contribution to the work of the Society would be very much missed.

The Chairman remembered Mr [GRO-A], mentioning his jaunty presence at meetings, his valuable contribution to the work of local Groups and the cheerful way he went about things. He, too, would be missed by all at the Society.

The Committee stood for a period of silent tribute to Mr [GRO-A] and Mr [GRO-A].

## **E91.01    Apologies**

Apologies for absence were received from Mr A Cowe and Mr K Colthorpe.

## **E91.02    Minutes arising from Executive Committee Meeting on 4 December 1990**

The minutes had been circulated in advance and it was noted that there was a correction to minute E90.61 at paragraph 3 which should read 'Liverpool' for 'Manchester'. Otherwise the minutes were adopted unanimously as an accurate record of proceedings, having been proposed by Mrs Hodgson and seconded by Mr Milne.

## **E91.03    Matters arising**

- a) **Compensation campaign:** Mr Watters said that there was little more to add to what had already been said about the campaign, but that the Society had received many appreciative telephone calls and letters. Mr Milne wished it to be recorded that a superb job had been done by Mr Watters and the Society, as well as all those connected with the campaign, and that a difficult victory had been won despite the understandable resignation with which the settlement had been accepted.

The Chairman said that efforts were now being concentrated on seeing that the Macfarlane Trust be replenished. In reply to letters sent by Mr Watters to both the Prime Minister and the Minister for Health assurances had been received that the Government would be keeping the Trust's funding under regular review. The Chairman said that the Trust was being encouraged to maintain, indeed increase, levels of payment and that accordingly the funds were diminishing. The machinery for dealing with the latest settlement was being prepared, and the money was expected in April, at the start of the next Government financial year.

- b) **Lease on 123 Westminster Bridge Road:** Ms Matthews reported that the lease was not yet completed, but would be soon.

Ms Matthews told the Committee that the freehold on the property had come up for sale. The Resources Committee had considered this matter and agreed that all steps should be taken to secure the freehold. Accordingly it had been valued by the surveyors, Edward Erdman, at £160,000 and the Society had put in a bid for £140,000. The success or otherwise of this would be known shortly. Mr Watters said that repayments on the loan necessary to secure the purchase would not exceed the annual rental payable.

- c) **North West Regional Health Authority:** Mr Watters reported that further to the Resolution from the November Council Meeting the Authority had now made an additional £516,000 annually for the provision of Factor VIII, and this met the predicted requirements of the Centre Staff.

## **E91.04    Follow-up to Horsted Place**

A paper had been circulated previously. Mr Barker outlined the main points, and proposed that a meeting take place before the Executive Committee Day on Saturday 11 May between the Chairmen and Senior Staff at which the clarification of roles and responsibilities would be worked out. The idea was endorsed by Mr Dickason and seconded by Mr Lawson.

## **E91.05    Medical Advisory Panel**

Mr Milne said that the subject had been raised by the Policy Committee and was fully supported by the Member Services Committee. There was a general feeling that the Society did not get a great deal out of the present system, and that perhaps other ways of extracting more out of the Panel should be devised. The Chairman said that the Panel had been established at a less dynamic time in the Society's history, and that if its performance was perceived as disappointing the Society should take it upon itself to change matters. The Committee agreed to the appointing of a Project Team consisting of Mr Watters, Mr Milne and Mr Cowe, serviced by Mr Barker, which would look at ways of accomplishing an overhaul. The Team could co-opt other people, and should consider including members of the Panel in its deliberations. Mr Watters suggested that the new improved Panel should take into account scientific as well as medical matters.

## **E91.06    Reports from Committees**

### **a)    Policy**

- i)    **Co-option of Mr Simon Taylor:** Mr Barker reported that Mr Taylor had been co-opted on to the Policy Committee. The Chairman suggested that he be asked to serve on the Executive Committee; this was proposed by Mr Miller, seconded by Mr Milne and agreed unanimously.
- ii)    **Campaign Update:** This had been dealt with under E91.03 Matters arising.
- iii)    **NHS Reforms:** Mr Barker reported that local District and Regional Health Authorities had been lobbied, and the response had been varied. Further letters had been sent, outlining what was happening in other regions around the country. Mr Barker felt that on the whole the response had been positive, and that the issue of haemophilia had been put on the agenda. Centre Directors had also been involved and again, there had been a varied response. A special edition of *Group News* had been sent to all local Groups. Mr Barker suggested that this should be followed up and that more direct support for Groups was needed through teaching such as was envisaged at the forthcoming Council meeting.

A paper entitled "Standards of Care that Patients should expect" had been drafted in consultation with Dr M Winter and circulated to the Policy and Member Services Committees, as well as to two Centre Directors.

The Centre Directors Organization, chaired by Dr E Mayne, had approached the Society to write a paper on standards of care, and the Department of Health had indicated that it would be interested in circulating this. The Committee was asked whether the Society should be involved in the production of a joint document. It was felt that the Society's position could be compromised, and that Mr Barker and Dr Winter's paper should be refined and presented to the Organization for adoption if they so chose.

Mr Dickason raised the issue of the cost of patients to GPs, and Mr Barker agreed to prepare an explanatory note on how the costing system would work. Mr Milne said that Groups ought to be encouraged to take an interest, and that possibly they did not feel confident or well-informed enough to ask questions of GPs and Centre Directors. It was agreed that this would be raised at the Council Meeting on Saturday 16 March.

- iv) **Policy Document:** Mr Barker reported that progress had been slow. He had been through past Executive and Council Minutes, and had asked the other Committees to submit suggestions.
  - v) **Public Relations:** Mr Watters reported that Health Network had submitted proposals for the forthcoming twelve months, and had been asked to revise them to exclude areas of marketing. He said that the Society had built up a good working relationship with Health Network, having worked with them since February 1990, and that they had extensive knowledge of and contacts with the health service at all levels around the country. They dealt with press and media relations, and had shown themselves to be sensitive and co-operative. In addition to that work it was also proposed that they would handle the editorial content of *THE BULLETIN* and *Update*. The Policy Committee requested that the Executive Committee empower it to enter into a contract with Health Network in an annual sum not exceeding £12,000. This was proposed by Mr Milne and seconded by Mr Miller and agreed unanimously.
- It was felt that there might be a risk of confusion over the possible over-lapping or tangling of work done in various areas, such as publications, public relations and fundraising, and Mr Dickason suggested that this be looked at with particular care.
- vi) **No Fault Compensation Bill:** Mr Barker reported that Rosie Barnes' Bill had been defeated on 1 February by 193 votes, and that there had been a debate on 20 February in the House of Lords on the subject. While there was no chance of any legislation at this stage, the issue was nevertheless on the political agenda.

#### b) Member Services

- i) **Annual Service:** Mr Milne proposed to the Chairman that he might consider holding a memorial service for those people with haemophilia who had died of HIV. The Chairman agreed to this suggestion, saying he would pursue the matter. He hoped a service could be arranged at Bishopgate before the autumn.
- ii) **One Day Regional Conference:** Mr Milne reported that this would take place in Huddersfield in July 1991.
- iii) **Availability of Social Work Service in Haemophilia Care:** A report had been received from Mrs Jean Lovie on behalf of BASW SIG, and the Policy and Member Services Committees were liaising on the matter.
- iv) **Hepatitis:** While it had been agreed at the Council Residential Weekend in November 1990 that hepatitis should be a priority for the Society Mr Watters said that legal advice had indicated that it could be unwise to pursue litigation. Articles about hepatitis were in the pipeline for *THE BULLETIN*.
- v) **Welfare Grants:** Mr Milne drew attention to the fact that there had been a fall in the number of requests for welfare grants, and suggested that the Macfarlane Trust was fulfilling some of those needs. It was felt that the Society's policy on grants was liberal.

c) **Resources**

- i) **Pisa Camp Funding:** The Chairman reported that a grant of £2,008 had been agreed for the summer Camp and that it had been agreed to underwrite the 1991 Camp to the extent of £3,500.
- ii) **North Wales Adventure Holiday Funding:** The Chairman reported that this had been underwritten for August 1991.
- iii) **Local Groups:** Mr Dickason reported on recent matters and there was agreement that a policy needed to be formulated on the running of camps, adventure holidays and caravans. Member Services agreed to look into the matter.
- iv) **Christmas Cards for 1991:** Mr Jack, Mr Colthorpe and Mr McDonald were reported to be liaising over this issue.
- v) **Terence Higgins Trust Candlelight Memorial:** It was reported that a grant of £100 had been agreed towards the Memorial.
- vi) **1990 Financial Position:** Ms Matthews had circulated Final Draft Accounts, but not all Committee members had received the document. Comments were asked for as soon as possible.
- vii) **McDonald and Associates:** Mr Watters circulated Mr McDonald's proposed Fundraising Action Plan for the period February 1991 to May 1992. This was not discussed.

c) **Grants Committee**

Mr Watters reported on the following:

- i) **Oxford Magnetic Resonance Imaging:** This project studied damage to joints through a complex scanning procedure, and a grant of £3,000 a year for 5 years was being requested. It was recommended by the Grants Committee that an initial £3,000 be given, with no guarantee of any subsequent funding.
- ii) **Dr Paul Winter, Belfast:** £1,475 had been requested for small items of equipment for the Genetic Laboratory. It was recommended by the Grants Committee that this application be paid in full.
- iii) **Dr G L Scott, Bristol Royal Infirmary:** Dr Scott asked that £2,000 be added to the existing grant (£6,300 for last year) which had not yet been taken up in order to pay an enhanced salary for a physiotherapist. This was recommended by the Grants Committee.
- iv) **Birmingham Children's Hospital:** Sister Gregory wished to furnish an over-night stay and interview room to a cost of £1,850. It was recommended by the Grants Committee that this be paid.
- v) **USSR Haemophilia Society:** It was recommended that an expensive computer project in Moscow be refused as the Society could not take on further overseas commitments.

- vi) **Dr French, Nottingham Haemophilia Centre:** Dr French had applied for help with funding the upgrading of a designated haemophilia treatment area at the Queens Centre. The total cost was estimated at £26,000. It was recommended by the Grants Committee that the Society 'pump prime' with a grant not exceeding £5,000, including any input from the local Group. The Society would help with additional fundraising.

Mr Miller proposed that the Committee accept these recommendations. This was seconded by Mr Milne and agreed unanimously.

#### **E91.07    Awards**

The Chairman asked for nominations before 16 March for the R G Macfarlane Award, the Haemophilia Society Award and the Local Group Award. Decisions would be made by the Chairman, Mr Cowe and Mr Milne and all suggestions would be circulated within seven days thereafter. There would be a further seven days allowed for comments.

#### **E91.08    General Secretary's Report**

The report had been circulated beforehand and the Chairman recommended it as comprehensive and well worth Committee members' study.

#### **E91.09    World Federation of Hemophilia**

A Project Team had been set up to consider the Blueprint for the 90s, but since Mr GRO-A's death there was a gap in the Team which Mr Milne agreed to fill.

Ms Matthews reminded the Committee that the Society's membership subscription to the Federation was due, and a decision required.

#### **E91.10    The Macfarlane Trust**

The Chairman reported that the Macfarlane Trust had moved into larger premises vacated by the SDP, and would be ready shortly to administer the next tranche from the Government.

#### **E91.11    Any Other Business**

Mr Watters raised the matter of the appointment of a Trustee for the Macfarlane Trust and the Chairman requested suggestions from the Executive Committee, within the same time scale as for the Awards.

**E91.12 Date of next meetings**

The next meeting of the Executive Committee will take place on Saturday 11 May 1991; the venue will be announced.

The Chairman asked that the subsequent Executive Committee meeting scheduled for Thursday 13 June be changed to Thursday 6 June. This was agreed.

**Approved as an accurate record of the meeting**

GRO-C

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

**6 June 1991**

RB 06.06.91