

Witness Name: Katherine Victoria Burt

Statement No.: WITN6392268

Exhibits: WITN6392269 – WITN6392280

**INFECTED BLOOD INQUIRY**

---

**WITN6392273**

---



## THE HAEMOPHILIA SOCIETY

The Haemophilia Society  
123 Westminster Bridge Road  
London SE1 7HR

Telephone: 0171 928 2020  
Facsimile: 0171 620 1416

### MINUTES OF THE EXECUTIVE COMMITTEE Wednesday 29 November 1995, at 3.00pm held at World Mission Association (WMA) Partnership House, 157 Waterloo Road London, SE1

#### Present:

The Rev Preb Alan Tanner (Chairman), Mr Chris Hodgson (Vice-Chairman), Mr Simon Taylor (Vice-Chairman), Mr Philip Dolan, Dr David Evans, Mr Gordon Clarke, Mr Andy Cowe, Mr Nick Lawson (Treasurer).

#### In Attendance:

Graham Barker (Director of Services and Development), Susan Archer (Registrar), Melissa Watson (Resources Clerical Officer).

#### AGENDA

- E95.71 Apologies for Absence
- E95.72 Minutes of the last meeting held on Friday 13/14 October 1995
- E95.73 Matters Arising
  - 95.61 Blood Products Policy
  - VAT on Recombinant Product
  - Macfarlane Trust
- E95.74 Committee Reports:
  - 74.01 Services Report
  - 74.02 Resources Report
- E95.75 Constitutional Review - Notes and Rules for Groups
- E95.76 Committee Structure
- E95.77 Hepatitis
- E95.78 Financial Assistance Grants
- E95.79 Membership Task Group
- E95.80 Any Other Business
- E95.81 Date, time and place of the next meeting
- E95.71 Apologies for Absence

Apologies were received from Mrs Norma Guy, Mr John Pepper, Mr Keith Colthorpe and Mr  
GRO-A

- E95.48 Minutes of the last meeting held on Friday 13/14 October 1995

Ms Archer read out a proposed amendment to the minutes of the meeting on the 20 September 1995.

#### CARING FOR PEOPLE WITH HAEMOPHILIA

Registered Charity No. 288260. A company registered in England and limited by guarantee. Registered Company No. 1763614

**E95.56 Approaches to the Patron**

The Duchess of Kent was approached by the Canterbury Haemophilia Trust rather than the Kent group.

It was noted that Mr Lawson was present at the last meeting.

**E95.64 Future of the Services Committee**

The following amendment was proposed by Mr Clarke.

The final paragraph should refer to The Chairman as suggesting that proposals go to Mr Barker rather than Mr Clarke.

These amendments were accepted by the Executive and the minutes approved.

**E95.73**

**Matters Arising**

**E95.61 Blood Products Policy:** Mr Barker reported on the distribution of the policy statement to the Executive. There had been no comments so the statement was approved as circulated. He will also issue it to the Medical Advisory Panel for information.

**VAT on Recombinant Products:** Mr Barker reported that he had written to the Department of Health and the Chairman to Kenneth Clark, Chancellor of the Exchequer, asking for the new VAT policy to be revoked, there has been no response from the latter. However the Department of Health has responded with a non-committal letter but there had been some press coverage on the issue.

Mr Taylor commented that it would be more competitive to have VAT on plasma products.

**Macfarlane Trust, Trustee Nominations:** The Chairman commented that Dr Mayne had recommended Dr Winter as a trustee. Mr Taylor agreed with this proposal. The Executive agreed that Dr Winter be approached and asked if he would allow his name to be put forward for consideration as a Department of Health appointee to the Macfarlane Trust. The Chairman enquired if any non-medical person had been suggested. Mr Taylor reported that Mr David Watters had declined the previous offer and referred to paper E95.61. The Executive discussed the two candidates: Kathy Stubbs (Haemophilia Social Worker) and **GRO-A** Mr Hodgson felt that Kathy Stubbs would be a good choice because of the changing nature of the Macfarlane Trust's responsibilities, for example, the increasing support needed for widows and children, which Ms Stubbs would be particularly sensitive to. Dr Evans commented on the suitability of Mr **GRO-A** because he has haemophilia, and possesses a good sense of judgement. The Chairman suggested that Mr **GRO-A** should be appointed and Ms Stubbs to be appointed when the next vacancy arises in March 1996. This was proposed by Mr Taylor and agreed by the Executive with three for and one against.

**E95.74**

**Committee Reports**

**74.01 Services Report**

Mr Barker reported on the minutes of the Services Committee meeting held on 16 November 1995

EHC: Mr Lawson enquired if the EHC had cost the Society any money. Ms Archer replied that it had, but the funding will eventually be provided by EAPPI and the European Community resulting in the Society making a profit. Mr Lawson requested that Ms Archer follow up the extra funding, she agreed.

Russian Twinning: Mr Taylor reported that the meeting with the Russian Society was very successful. The Chairman enquired about product availability in Russia. Mr Taylor stated that individuals outside Moscow have to buy blood products from a blood bank and go to a centre to have it administered. Moscow is asking for know-how, expertise, English teaching, particularly for those who are disabled. The Chairman asked whether there is a chance of receiving Overseas Development Aid, Mr Taylor replied that he was optimistic about the Society being granted it.

Equal Opportunities Service Provision: Mr Taylor reported that Mandy Cheatham had requested equal opportunities in terms of e.g. language variations in booklets, to be raised. The Executive agreed to put it on the next agenda.

#### 74.02 Resources

Office Premises: Ms Archer referred to paper E74.02.02 and requested that the situation be re-considered and whether the Society should move to new premises, because the current premises have un-finished structural changes and difficulty of access. Mr Lawson suggested signing the lease and finding an organisation to take it over. He also reported that the signing of the lease is being suspended until the changes are complete. The lower rent allowed for the period of renovation cannot be demanded until the lease has been signed, therefore adding to the sense of urgency to make a decision. The Committee agreed that the lease should be signed and new premises be sought.

Fund-raising & Expenditure: Ms Archer apologised for not providing a full financial report. The current deficit of £35,000 was partly explained by: EHC funding still being owed to the Society, the Annual Draw not raising as much money as last year and the Birchgrove Group joining the centralised banking scheme, leading to an increase in HIV expenditure.

The section 64 grant application has passed through the Finance Committee and is awaiting ministerial approval; the Society will hear whether it is successful in January.

Mr Clarke raised the issue of adventure holidays. Ms Archer commented that she has written to the North Wales Group, and will report further at the next meeting.

Mr Taylor expressed concern about the approaches to Dame Catherine Cookson suggested by Mr Berry. Ms Archer commented that he would not approach her unless he had the full approval of the Committee.

Staffing: Ms Archer reported on staffing. The new Children & Families Worker has been appointed. The closing date for applications to the position of Administrative Resources Officer is 30 November. The Chairman enquired who would be interviewing the candidates, Ms Archer replied that it would be Mr Berry and herself.

E95.75

#### Constitutional Review

Ms Archer reported that the Notes and Rules for Groups had been circulated to Executive and Group Officers and requested that any comments be made in writing. They will be discussed further at the Council meeting on 9 December. Mr Barker questioned the definition of the relationship between Special Interest Groups and Task Groups. It was suggested that Special Interest Groups are involved in Task Groups rather than "represented" on them. This was agreed.

E95.76

#### Committee Structure

Mr Barker introduced three new committee structure proposals put forward by: Dr Evans, Mr Pepper and Mr Dolan. Dr Evans proposal was to maintain the present structure, with possibly some flexibility regarding the task groups, and the sub-committee that would be responsible for them. The second set of proposals were put forward by Mr Pepper. These were a) disband the Services Committee and substitute task groups, b) create two sections of the Services Committee - Specialist Services and General Services, c) arrange for everything to be dealt with by the full committee and thereby eliminate the need for any Sub Committees. The third proposal favoured by Mr Dolan is that of abolishing the Services Committee with its responsibilities going to the Executive Committee. However he made the point that he would be happy to stay with the Services Committee if that was the Executive's final decision.

Mr Barker reported that there had been no costings made for the proposed changes. Mr Taylor commented that he felt there ought to be additional task groups if the Services Committee was disbanded, plus a mechanism by which they could be set up as and when they were needed.

Dr Evans commented that constantly changing the structure is not an effective way of running an organisation. The Chairman asked the staff for their opinion on the proposed changes. Mr Barker commented that three tiers was too many, recommendations from task groups get lost in the services tier, thus demoralising some task group members when their views are not being heard at executive committee level. There is also a lot of duplication of effort. Mr Clarke proposed that any changes should be executed expediently. Mr Taylor agreed and felt the issue had been on the agenda for too long. He proposed to disband the Services Committee, and to discuss at the next meeting the potential for more task groups. This was agreed by the Committee.

E95.77

#### Hepatitis

Mr Barker gave an update on the parliamentary campaign. The EDM had been re-tabled with all existing signatories, around 250, giving their support. Mandy Cheetham, the Hepatitis Research Worker had produced an interim report which is going to be mailed out to all the supporting MP's and to the Secretary of State. John Marshall, MP is intending to ask an oral Parliamentary question to obtain the Minister's response. Press coverage in the Daily Telegraph is expected. The Manor House Group have a meeting with Stephen Dorrell, where a highly representative group of delegates will attend, including a mother of two children with hepatitis C. It was agreed that the delegates should stay overnight with expenses paid. The Society will not have any official at the meeting.

E95.78

#### Financial Assistance Grants

Mr Barker had highlighted at the last meeting the increasing number of applications for financial assistance from people who were infected with hepatitis C, their difficulties directly arising from their infection rather than haemophilia. He therefore asked the Executive to reconsider the criteria for eligibility for a grant. Mr Taylor commented that some of the requests should be met, but that a set of rules ought to be established due to limited funds. Mr Clarke agreed with the Executive and felt there was a risk of 'opening the floodgates', though it would provide anecdotal evidence for the Government showing that there is a need.

E95.79

#### Membership Task Group

Mr Hodgson reported on the membership development work he had been conducting (paper E95.79). The Committee endorsed the objectives set out in the paper E95.79. For example he reported that the Lincoln group wishes to see more of the Society. Mr Barker commented that liaison between the executive members and groups is already taking place at a relatively low cost because pharmaceutical companies have been sponsoring the meetings. Mr Hodgson reiterated that he is asking for suggestions from the Executive committee, and that they should be sent to Mr Barker by the end of the year.

E95.80

#### Any Other Business

Mr Taylor asked the Chairman to write to Dr Winter and Mr Jenkins to inform them of the new Committee changes and that they were no longer needed to attend that Committee. He also requested a consolidated Executive report which is itemised for reporting and decision etc, to be prepared by Ms Archer, for the next Executive meeting.

Dr Evans enquired whether funding had been obtained for the new parents video. Mr Barker replied that at the last Executive meeting it was agreed that the Society would pay for the remainder.

E95.81

#### Date and Time of Next Meeting

The next meeting will take place on 31st January at 3.30pm, at the WMA, Partnership House, 157 Waterloo Road London SE1.

GRO-C

Signed:

The Reverend Prebendary Alan J Tanner

Date: 31 January, 1996

T:\executive\minutes\min2911.doc311996