Witness Name: Katherine Victoria Burt Statement No: WITN6392001 Exhibits: WITN6392002 - WITN6392267

# INFECTED BLOOD INQUIRY

## WITN6392209



THE Haem**ophili**a Society The Haemophilia Society 123 Westminster Bridge Road London SE1 7HR

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## MINUTES OF THE EXECUTIVE COMMITTEE MEETING on Thursday 7 July 1994 at 4.00pm, held at Central Office of Information (COI), Hercules Road, SE1

### **Present:**

Rev Prebendary Alan Tanner (Chairman), Mr Simon Taylor and Mr Chris Hodgson (Vice Chairmen), Mr Nicholas Lawson (Treasurer), Mr Keith Colthorpe, Mr Andy Cowe, Dr David Evans, Mrs Norma Guy, and Mr Julian Lander

#### In Attendance:

Mr Graham Barker (Director of Services and Development), Ms Susan Archer (Registrar) and Miss Jeni Mason (Resources Clerical Officer).

## AGENDA

| E94.43 | Apologies for Absence                                   |
|--------|---|
| E94.44 | Minutes of the last meeting held on Saturday 7 May 1994 |
| E94.45 | Matters Arising   |
| 45.0   | 1 Executive Committee Members visits to local Groups    |
| E94.46 | Constitutional Review                                   |
| E94.47 | Committee Reports:                                      |
| 47.0   | 1 Services  |
| 47.0   | 2 Resources   |
| E94.48 | Any Other Business                                      |
| E94.49 | Date and Time of next meeting                           |
|        |   |

E94.43 Apologies

Apologies were received from Mr Gordon Clarke, Mrs Carol Holliday and Mr John Pepper.

## E94.44 Minutes of the last meeting held on Saturday 7 May 1994

It was noted that Mr Andy Cowe was present at the meeting. The minutes were recorded as a true record.

## E94.45 Matters Arising

# **45.01** Executive Committee Members visits to local Groups: Ms Archer raised the question on the procedures for Committee Members reporting their visits to local Groups. The Committee agreed that a report on each visit would be cart to Ma Archer

to local Groups. The Committee agreed that a report on each visit would be sent to Ms Archer at the national office.

## CARING FOR PEOPLE WITH HAEMOPHILIA

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Whilst on the subject of Groups Mr Barker reported that the existing Officers of the Oxford Group are proposing to stand down at their next AGM and that replacements are unlikely. The Committee agreed that Graham Barker and Chris Hodgson arrange to visit the officers to discuss the issue.

## E94.46 Constitutional Review

Ms Archer referred to the discussion paper that had been previously circulated, highlighting the fact that most of the views were on amalgam of discussions with others and written submissions received by 30 June 1994. The views on membership, however, were her own.

The Chairman invited comments from the Committee and after a brief discussion it was agreed to leave the matter to the Task Group for a more detailed paper to be presented at the next meeting.

## E94.47 Committee Reports:

## 47.01 Services:

The Services Committee held their meeting prior to the Executive meeting. Mr Barker circulated his services Committee report to all members of the Executive. Mr Taylor gave a brief report on the issues arising from the meeting.

## **Blood Products:**

Bayer had launched their recombinant factor VIII product Kogenate. Mr Taylor reported that the Society attended the launch meeting but not did not attend the press conference, although Mr Colthorpe had as an individual who was using the product.

## **Publications:**

Introduction to Haemophilia is currently being revised. As yet no sponsorship has been received. The Services Committee agreed that monies originally set aside for other publications would be used for this purpose. Sponsorship was still being sought. The Treasurer noted this decision.

## **Financial Assistance Grants:**

Draft guidance would be produced for the next Services Committee meeting following consultation with members of the working Group.

#### **Prophylaxis:**

Following a meeting recently held in Cambridge for a wide range of representatives from European countries with an interest in haemophilia organised by Dr Geoff Savidge, a consensus statement on the use of prophylaxis had been produced. Discussions have taken place with Munro and Forster on how the promotion of prophylaxis for children could be taken forward. The Services Committee will report on the progress.

## **HIV Task Group:**

The first meeting of the Task Group, which consisted of Norma Guy, Simon Taylor, GRO-D GRO-D GRO-D GRO-D GRO-D GRO-D GRO-D GRO-D Graham Barker and GRO-D GRO-D took place on 27 June. The Group made a number of recommendations. The Services Committee agreed a statement put forward by Graham Barker and presented this to the Executive Committee for approval. This outlined the support that the Society would give to people with haemophilia and HIV. The Executive endorsed this statement. The Executive Committee also endorsed the Services Committee decision to give the Birchgrove Group £7,500 for core funding and £2,500 for their conference, subject to certain assurances, that the status of the Birchgrove Group is such that the position of the Executive Committee as Trustees is not compromised by making this grant.

## Hepatitis:

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The Hepatitis Task Group will shortly meet to review the meetings held in London, Leeds, Edinburgh and the most recent in Bristol. Major issues arising from these meetings include the lack of information given by Centres; the failure to notify people that they are HCV positive; the range of liver tests that are available; access to interferon and the life style that should be pursued. The Task Group will consider what action to take and will also discuss the medical negligence and compensation issues raised by Mr GRO-A

#### Chairman's Conference:

A draft programme was circulated with the Services Committee report and presented to the members of the Exectuvie Committee. The Committee noted the programme.

### 47.02 Resources:

The Resources Committee also held their meeting prior to the Executive meeting and the Treasurer, Mr Nicholas Lawson, briefly outlined the issues.

## Income and Expenditure:

The Treasurer advised the Committee that as a result of <u>GRO-D</u> direct approach to a Trust in the Channel Islands the Society had received a donation of £25,000. This is a considerable boost to the Society's funds and the Treasurer congratulated John for his achievements. Otherwise, the Treasurer reported that funds received exceed income but that as we still have not yet received any legacies, vigilance should continue.

#### **Office Premises:**

The freehold was recently sold to Transmarine Shipping Agencies, the Society's next door neighbours, at the purchase price of £90,000. The Society has three options:

- i) carrying on negotiating with them to occupy the building
- ii) stay a short time and then leave or
- iii) to go immediately

Mr Lawson assured the Committee that negotiations are in the capable hands of <u>GRO-D</u> The Committee agreed that MGRO-D hould continue to negotiate with Transmarine. The Committee was asked to note that access to the car park at the rear of the building ceases on 31 July 1994.

#### Victorian Ball:

Mr Hodgson briefly outlined the progress on the Ball. Telesmart are making good progress in selling Ball Tickets. The Society has provided a list of contacts, including Haemophilia Centres, Pharmaceutical Companies and corporate supporters. Mr Hodgson and the Reverend Prebendary Alan Tanner are meeting with Telesmart on Thursday 14 July at 10.00am. The progress of that will be reported at the next meeting.

#### Database:

Ms Archer and Mr GRO-D had seen two Database demonstrations. Ms Archer will make the final decision after a third demonstration has taken place on Monday 11 July and will inform the Committee of the decision.

## Health Network:

Health Network's contract with the Society has run for three years without review. A proposal for an increase had been presented to the Resources Committee who sought the further advice of the Executive Committee. The Committee discussed this at length and agreed that the Society should carry on using the services that Health Network provide at the increased fee.

## **Group Activities:**

## **Birmingham Group, Chalet Purchase:**

The Birmingham Group has requested permission to purchase a holiday chalet in Hemsby, Nr Great Yarmouth in Norfolk. The Group are concerned that their present caravan is not appropriate or accessible for many people with haemophilia and their families. The chalet has low running costs and would be a valuable asset for the Society. The Group are willing to launch a fund raising campaign towards the purchase, and would be happy if other Groups wanted to become involved. The Committee agreed that Keith Colthorpe would take a look at the chalet and report to the next Executive Committee meeting for their decision.

#### Northern Ireland Group AGM:

The Northern Ireland Office sought permission to spend £2,000, as last year, on their Annual General Meeting. To date the Group have contributed £7,500 via the centralised banking fund. The Committee agreed this proposal.

## E94.48 Any Other Business

There was no other business that was not already covered in the minutes.

#### E94.49 Date and Time of next meeting

The next meeting will take place on Wednesday 8 September at COI, SE1

A meeting of the Officers will take place on Thursday 28 July at Lawson International.

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