

Witness Name: Katherine Victoria Burt

Statement No.: WITN6392268

Exhibits: WITN6392269 – WITN6392280

INFECTED BLOOD INQUIRY

WITN6392277



**THE
HAEMOPHILIA
SOCIETY**

The Haemophilia Society
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MINUTES OF THE EXECUTIVE COMMITTEE
Tuesday 2 May 1995, at 16.45pm
held at World Mission Association (WMA)
Partnership House, 157 Waterloo Road, London, SE1,

Present:

The Rev Prebendary Alan Tanner (Chairman), Mr Simon Taylor and Mr Chris Hodgson (Vice Chairmen), Mr Nicholas Lawson (Treasurer), Mr Gordon Clarke, Mr Andy Cowe, Dr David Evans, Mrs Norma Guy, Mr John Pepper.

In Attendance:

Mr Graham Barker (Director of Services and Development), Ms Susan Archer (Registrar), Ms **GRO-A** (Resources Clerical Officer).

AGENDA

- E95.20 Apologies for Absence
- E95.21 Minutes of the last meeting held on Saturday 1 April 1995
- E95.22 Matters Arising
 - E95.16 Annual General Meeting
- E95.23 Hepatitis:
 - 23.01 Campaign
 - 23.02 Hepatitis Task Group
 - 23.03 Hepatitis Worker
- E95.24 Services Committee Report
- E95.25 Resources Committee Report
- E95.26 Constitutional Review
- E95.27 Committee Membership/Role of Task Groups
- E95.28 Any Other Business
- E95.29 Date, time and place of the next meeting

E95.20 Apologies for Absence

Apologies were received from Mr Keith Colthorpe and Mr Julian Lander Mrs **GRO-A** was not in attendance.

E95.21 Minutes of the last meeting held on Saturday 1 April 1995

The minutes were agreed as a true record. This was proposed by Mr Hodgson and seconded by Mr Clarke.

CARING FOR PEOPLE WITH HAEMOPHILIA

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E95.22 Matters Arising

Trustees appointed by the Haemophilia Society:

At the Executive meeting on 9 February 1995 the Committee discussed the position of its nominees to the Macfarlane Trust and agreed to re-appoint three Trustees, The Rev Preb Alan Tanner, Mr C Grinstead and Mrs N Guy for a further two year term of office. However, Mr Barker reported that the position of Mr Hodgson and Mrs Sheila Cowe, had not been regularised as trustees. The Committee agreed for a further two year term of office for these two trustees. Mr Hodgson to March 1996 and Mrs Cowe to August 1996. This was proposed by Mr Taylor and seconded by Mr Clarke.

Mr Barker also stated that Mrs Margaret Brierley's term of office ends in November. He asked the Committee whether it wishes to re-appoint Mrs Brierley for another term of office. The Chairman suggested that Mr Barker discuss this with Mrs Brierley to see whether she would like to continue.

E95.16 1995 Annual General Meeting

Ms Archer reported that the AGM will be held in St Thomas' Hospital in the Prideaux Theatre and not in the Nevin Lecture Theatre as previously reported. Ms Archer confirmed that Dr Mark Winter will be the speaker and is scheduled to speak at 14.00pm.

E95.23 Hepatitis:

23.01 Campaign

Mr Barker circulated a Hepatitis Campaign report at the meeting. He briefly outlined the activities of the campaign. He reported that the campaign had been launched on 14 March and as a result there had been some TV and radio coverage but no national newspaper coverage.

A press release had been sent to all MPs inviting them to support the campaign. Mr Barker said that over a 100 had replied positively. A letter had also been sent to members asking them to write to their local MP. Again, there was a positive response.

Mr Barker reported that John Marshall MP and Sir Geoffrey Johnson-Smith had met with Gerald Malone, Minister of State for Health, to present the Society's case. Mr Malone had listened to the MPs and agreed to respond in due course. A reply was still awaited.

Mr Barker reported that a written reply from Tom Sackville, Parliamentary Under Secretary for Health, (a copy of which was attached to the campaign report) had been sent to all MPs who wrote to the Secretary of State for Health about haemophilia and hepatitis C. The letter was mainly about treatment and research. The questions of financial recompense had not been addressed.

Mr Barker reported that 20 MPs had attended an All-Party meeting held on Wednesday 26 April at the House of Commons. After a short presentation by the Chairman the MPs discussed how they could support the campaign. Mr Barker summarised the points that were made during the discussion.

The Committee agreed that the possibility of legal action against the Government should be kept under review as proposed by one of the MPs present. If an announcement of an offer from the Government was made the full Executive Committee would be consulted on the Society's response.

23.02 Hepatitis Task Group:

Mr Barker reported that this item had been covered in the Services Committee minutes, previously circulated, and had nothing further to report.

23.03 Hepatitis Worker:

Mr Barker reported that Ms Mandy Cheetham had been appointed as the Hepatitis Worker and that she will start her post on 7th June 1995. Ms Cheetham has a background on Hepatitis and HIV related work. The post is on a six month contract but would be reviewed after four months.

E95.24 Services Committee Report

Minutes of the last Services Committee meeting were previously circulated. Mr Taylor highlighted areas to be noted.

HIV:

Mr Taylor reported there had been a series of helpful meetings with the Birchgrove Group and the HIV Task Group to discuss what the Society should be doing on HIV.

European Hemophilia Consortium:

Mr Taylor requested, with the permission of the Chairman, the dates scheduled for the EHC meeting scheduled for 13/14 October, be changed with the Executive Committee meeting scheduled 20/21 October. This was agreed. He confirmed that the expenses for the conference would be in the range of £20,000. £15,000 had been received; £5,000 from the European Community and £10,000 from a sponsor, who at present wishes to remain anonymous. The remaining £5,000 would be sought from other sponsors.

Memorial:

Mr Taylor reported that the Services Committee had made some suggestions for commissioning a monument in memory of people with haemophilia who have died of AIDS. Mr Taylor felt that the memorial should be situated in London. The Chairman expressed concerns that a public place might not be appropriate for the families of those who have died. The Chairman proposed that further thought be given to this subject and requested that he be involved in these discussions.

E95.25 Resources Committee Report

The Resources Committee met prior to the Executive Committee meeting. Mr Lawson and Ms Archer reflected on some of the areas covered in the meeting.

1995 Income and Expenditure:

Mr Lawson reminded the Committee that financial report to the end of March 1995 had previously been circulated. In terms of income, Mr Lawson commented that the Society was doing reasonably well.

Fund-Raising:

A written report from John Berry was circulated. Mr Lawson reported that we had been promised, by the Department of Health, money amounting to £35,000 for HIV and £91,000 Hepatitis work.

Office Premises:

Mr Lawson reported that the questions about VAT have been resolved and will not be included in the rent. We await information about the proposed alterations to the ground floor.

Caravans Review:

The Resources Committee had discussed the income received from Caravan and Chalet rentals received by Groups. Mr Lawson felt that the Society would benefit more if the caravans and chalets were let to people other than families with haemophilia when they would otherwise be vacant. It had also been suggested that there be a co-ordinator of caravan and chalet use. The Resources Committee had earlier suggested that Mr Colthorpe might like to do this. The Committee agreed that this was a good idea but felt that in the absence of Mr Colthorpe Ms Archer formally discuss it with him.

Staffing Proposals:

Ms Archer reported that Kate Richards, Member Services Officer, would not be returning to the Society following her **GRO-A**. A proposal for replacing her had been presented to the Services Committee at their last meeting. This had now been costed, and also approved by the Resources Committee. The agreed proposal offers Shanit Marshall a full-time position as Information and Advice worker as she had been acting this role while Kate Richards **GRO-A**. **GRO-A** Ms Archer reported that a new clerical officer would be appointed. The Executive Committee agreed to that Ms Marshall be promoted to the new post and requested that Ms Archer carry out the necessary arrangements to recruit a new clerical officer.

Resourced Programme:

In a letter to the Chairman Mr Pepper proposed that a resourced programme be implemented by the Resources Committee. This was approved by the Committee. Mr Pepper agreed to send a draft programme to Ms Archer for discussion and implementation.

HIV Funding:

Mr Taylor asked what had been done about seeking funding from specialist HIV agencies. Ms Archer reported that initial research into the types of funding available was underway but, there needed to be a dialogue between Services and Resources before any applications could be made, in that, we need to know what we are seeking funds for.

E95.26

Constitutional Review:

Following the Council Meeting on 1 April 1995, Mr Cowe and Ms Archer met with Anne-Marie Piper of Paisner & Co to discuss rewriting the Memorandum and Articles. Mr Cowe highlighted areas of concern expressed by Anne-Marie Piper. These were:

Membership:

It was agreed that the definition of members needs to be clarified and that we need to decide which model of membership to adopt. Ms Piper's interpretation of the current situation is that everyone is a legal member of the company. Mr Cowe presented the three options for discussion:

- i) **All members are members of the company.** This is the current situation.
- ii) **Ruling Oligarchy.** Only the Trustees are members of the Company
- iii) **Two tier membership:** The membership could be split into a two tier membership to identify those who would want to have the right to vote and those only wishing to receive the Society's publications.

The Committee preferred the third option above. There should not be an option for free membership for people or organisations only wishing to be on the mailing list.

Trustees:

There was agreement that the introduction of terms of office was good practice and that there are standard clauses for the Articles of Association that will cover this. It was Ms Piper's view that inclusion of arrangements when not enough candidates for election would make the Articles too complicated.

Council:

Mr Cowe reported that standard clauses exist that will describe the role of the Council. Ms Piper had some concerns about the roles of Groups, in particular the special interest groups, and had suggested a meeting with representatives of the two special interest groups to discuss their relationship to the Society. Mr Taylor, as a member of the Birchgrove Steering Group, agreed to take soundings from the Birchgrove Group, and Mr Cowe agreed to continue his dialogue with the Manor House Group.

Mr Cowe reported that the next steps are to arrange the above meeting with the special interest groups, and for the Paisner & Co to draft out the new Memorandum and Articles. These would be presented at an EGM towards the end of this year with a view to implementing the new system by the AGM in 1996. It was agreed that Mr Cowe would report this at the AGM.

E95.27 Committee Membership/Role of Task Groups

A letter from Mr Pepper to the Chairman setting out observations and proposals for consideration was circulated. Some of the proposals had already been discussed at the Resources Committee meeting. The Chairman invited the Committee members to comment on the proposals outlined. There was a brief discussion, and the points made were noted

E95.28 Any Other Business

Awards:

Ms Archer informed the Committee of the nominations for Awards.

Award: There had been two nominations, **GRO-A** and **GRO-A**. **GRO-A** The family of **GRO-A** requested that **GRO-A** be given for the award as he was approaching the end of his music degree. They would write personally to **GRO-A** encouraging him to re-apply in the future. The Committee agreed to give the award to **GRO-A**. The cheque will be presented by **GRO-A**.

Groups Award: Susan Lander, Treasurer of the Merseyside Group, has been nominated for this award. The Committee agreed to present this award.

Groups:

Ms Archer reported that at their recent AGM, the Birmingham Group had decided to disband. The Committee expressed their concern at this development, and Mr Cowe offered to discuss the matter with people attending the Hepatitis Day in Birmingham on Saturday 6 May.

Start time of meetings:

Dr Evans requested that future, week day, meetings of the Executive Committee start at 3.00pm. This was agreed.

E95.29 Date, time and place of the next meeting

The next meeting will take place on Thursday 15 June at 3.00pm. The venue will be at WMA, Partnership House, Waterloo Road, SE1, and will be held in room (B).

Signed:

GRO-C

The Reverend Prebendary Alan J Tanner

Thursday 15 June 1995

The executive minutes m2may95.doc 11.05.95