

Witness Name: Katherine Victoria Burt

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**INFECTED BLOOD INQUIRY**

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**WITN6392251**

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# THE HAEMOPHILIA SOCIETY

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## MINUTES OF THE SERVICES COMMITTEE MEETING held on Thursday 16th November 1995 at the World Mission Association, 157 Waterloo Road, London SE1 8XA

### Present

Mr Simon Taylor, Vice Chairman, Mr Paul Jenkins, Mrs Norma Guy, Dr David Evans, Mr Philip Dolan, Dr Mark Winter, Mr Andy Cowe, Mr John Pepper.

### In Attendance

Mr Graham Barker, Director of Services and Development, Ms Shanit Marshall, Information and Advice Worker, Ms Mandy Cheetham, Hepatitis C Research Worker, Ms Evangelie Polyzos, Secretary and Administrative Assistant.

### B95.51 Apologies

Apologies were received from Mr Cady Khudabux.

### B95.52 Minutes of Meeting held Tuesday 12th September 1995

The minutes were accepted as an accurate account of the meeting.

### B95.53 Matters Arising

#### a) B95.42 c) ii) Observer status at Macfarlane Trust meetings

The Executive Committee had rejected the proposal to seek two observers at Trust meetings. The next meeting of the Trust (21st November) would consider the question of making the minutes available to the Society.

#### b) B95.46 iii) WFH Congress Dublin 1996

The WFH Congress in Dublin next year will be advertised in the next issue of the Bulletin. People will be asked to put forth reasons why they should be selected as part of the delegation to attend the congress. It has not been decided how many will be attending the meeting; this will be dependent on sponsorship, though it is expected that 6-7 people will be attending. The people best able to represent the Society effectively and who will get the most out of the meeting will be the basis for selection.

#### c) B95.47 Activities for 1996

The Activities for 1996 discussed at the previous meeting were all taken forward and have gone into the budget for next year with the exception of adventure holidays. The availability of sponsorship will determine which activities will go ahead.

## CARING FOR PEOPLE WITH HAEMOPHILIA

**d) B95.49 c) Cardiac Arrest**

The BBC have agreed to make the following announcement at the end of the next showing of Cardiac Arrest (either the repeated episode or a new series).

"An episode in the last series of Cardiac Arrest featured a patient with haemophilia who died within minutes when his nosebleed developed into a major haemorrhage. We would like to make clear that rapid and fatal bleeding if this kind is extremely rare, and no more likely to happen to someone with haemophilia than to anyone else."

**e) Publications**

Mandy Cheetham's investigations into the cost of translating some of the Society's publications into other languages showed this to be an expensive task. It was agreed that Mandy would draft a piece for the next issue of the Bulletin asking for any volunteers able to translate the Society's publications.

**B95.54 Hepatitis**

**a) Campaign Update**

It was reported that Alf Morris's Early Day Motion was retabled on 15th November. The motion has attracted 233 signatures from MPs. Only 3 MPs signatures were lost from the original list. Other MPs will be contacted for their support. An article about the campaign and the motion was also published in the Daily Telegraph on 15th November. Simon Taylor and Mark Weaving are working on approaching a major newspaper to publicise the campaign. Mark Weaving has also set up 8-10 interviews with the local and regional press for people to talk about their personal experience of HCV.

**b) Update on Other Activities**

i) Mandy Cheetham's post has been extended until March. This will enable her to continue her research. She aims to:

- a) Examine the impact of Hepatitis C on individuals.
- b) Visit more centres
- c) Address the problems of access encountered by youths.
- d) Extend her research to a more broad geographical spread.

ii) Mandy will also be producing some fact sheets

Possible subjects include:

- a) Risks of transmission
- b) Employment
- c) Diet
- d) Family Planning
- e) Alcohol
- f) Support and monitoring - advocacy work.
- g) Education
- h) Developing a peer support service
- i) Need for counselling in centres.

(iii) It was reported that the London Hepatitis meeting had been successful and 80 people attended. Dr Mutimer had been replaced by Dr Wong, a Research Fellow from Cambridge. The meeting proved that there was still a strong need for information.

#### **B95.55 HIV Task Group Report**

##### **a) World AIDS Day**

It was reported that a greeting card would be sent to members to help raise awareness. A grant of £750 from the Department of Health had been received, and the Birchgrove Group agreed to cover the cost of producing the card.

##### **b) Guidelines on Good Practice for HIV Treatment**

The Group discussed issues like whether patients were getting the best possible treatment from their doctors and hospitals as well as access to services available. Dr Christine Lee the chair of HCDO HIV Working Party had been asked to update the material she had and to issue this as guidance to all haemophilia centre directors.

Two pieces would be published in future issues of the Bulletin:

- (i) one would be a personal piece on where patients stand with regard to attending different centres from their own
- (ii) the other will be a more technical piece on getting a second opinion and access to other medical services.

A piece on the Delta Trial will also be produced for the next issue of the Bulletin.

##### **c) Commemoration**

The North West group will be planting a tree at Victoria park by Royal Manchester Hospital next week. There will also be a tree planted in Salford near the Children's Hospital, in the public park. The mayor will be present. This will be publicised in the next Bulletin to encourage other local groups to do something similar.

Dr Winter raised the question of the memorial and Simon Taylor agreed to raise this at the Executive Committee meeting.

#### **B95.56 Macfarlane Trust**

##### **a) Society appointment**

It was reported that the Society was still looking for eligible people for consideration as trustees on the Macfarlane Trust. Philip Dolan requested that details about nominees should be made available before discussion at the next Executive.

##### **b) Centre Director Nominations**

Members were asked to put forward their suggestions for Dr Mayne's replacement as Centre Director on the Trust.

#### **B95.57 Support for Parents**

##### **a) Task Group Report**

- i) The Society has received funding to hold 2 one day events for parents with children with haemophilia.

ii) The Parent Support Network will be launched after the Children and Families Worker has settled into his post in the new year. The Worker will provide ongoing support for the volunteers.

iii) The next meeting of the Task Group will be on 5th December 1995.

**b) Update on Other Activities**

i) Peter Brown a social worker from Camden Social Services has been appointed Children and Families Worker. He will start in January.

ii) It was decided that more needed to be done to actively involve young people in the Society. It was noted that funding was available from the WFH to send a young person to Dublin for the Congress in 1996. An advertisement would be placed in the next Bulletin.

iii) Dr Winter reported that Bayer were producing a diary for young people with haemophilia.

iv) It was agreed that Task Group minutes be circulated to all members of the Executive.

**B95.58 Blood Products**

a) Dr David Evans had redrafted the Society's Policy Statement which would be reconsidered at the Executive Committee on 29th November and submitted to the MAP for information.

b) It was agreed that more pressure needed to be applied in order to change the decision to impose VAT on recombinant products. It was suggested that a letter be sent to the Chancellor before the next budget, November 28th and released to the press. The European dimensions would also be investigated.

c) The Committee endorsed the Society's publicly stated position on selling Factor VIII abroad. Namely that:

a) There are no shortages in the UK.

b) The revenue generated is used for patient care and not lost to the Treasury;

c) There is no detrimental effect on UK donors continuing to donate blood.

The Committee also agreed that it would like BPL to establish a system whereby people who are in need of blood products could get hold of them. It was suggested that a programme with the Russian Society could be developed where the distribution of concentrates could be controlled and used for emergencies only and not for day to day use. It was hoped that this could be developed between the WFH and BPL

**B95.59 European Haemophilia Consortium Conference 20-22nd October 1995**

It was reported that the European Haemophilia Consortium went very well with 27 countries and over 90 people attending. The conference gave people the opportunity to share and exchange information, experiences and discuss mutually relevant issues. The next meeting will be held in Turkey next Autumn.

**B95.60 Twinning with the Russian Haemophilia Society**

It was reported that Simon Taylor and Andy Cowe had a very successful meeting with the Russian Haemophilia Society before the start of the EHC meeting. The Russian Society would like help with

issues such as education, learning english, training, etc. They would also like help with training in areas such as:

- a) How to manage a voluntary organisation.
- b) Public Relations, and
- c) Access to training specialists in the West.

Simon Taylor agreed to look at funding sources including Overseas Development Aid from the Government. He agreed to compile a list of possible activities for discussion with the Russian Society in the next few months. A three to four day exchange system with Russia was suggested as one possibility.

**B95.61 Any Other Business**

It was requested that the issue of Equal Opportunities in relation to services provided by the Society be on the next meeting's agenda.

**B95.62 Date and Time of Next Meeting**

To be notified at a later date subject to the Executive Committee's decision on the future of the Services Committee at their next meeting.