

Witness Name: Katherine Victoria Burt

Statement No.: WITN6392268

Exhibits: WITN6392269 – WITN6392280

**INFECTED BLOOD INQUIRY**

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**WITN6392275**

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# THE HAEMOPHILIA SOCIETY

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Patron: HRH The Duchess of Kent  
President: Dame Catherine Cookson

## MINUTES OF THE BOARD OF TRUSTEE MEETING

Thursday 24th July 1997

Starting at 3pm at the Haemophilia Society  
3rd Floor, Chesterfield House  
385 Euston Road, London, NW1 3AU

### Present:

Mr Christopher Hodgson (Chairman), Mr Gordon Clarke (Vice-Chairman), Mr Nicholas Lawson (Treasurer), Mrs Mary Clark (Trustee), Mr Stan Cockburn (Trustee), Mr Philip Dolan (Trustee) [part of meeting], Mrs Jan Hardy (Trustee), Mrs Carolyn McGimpsey (Trustee), Mr John Pepper (Trustee) and Mr Bob Purnell (Trustee).

### In attendance:

Mr Graham Barker (Director of Services), Mrs Sue Rocks (Membership Officer) and Mr Tony Wilson (Chief Executive).

### Agenda

- T97.25 Apologies
- T97.26 Minutes of last meeting held on 30th May 1997
- T97.27 Matters Arising
- T97.28 Election of Presidents
- T97.29 Tanner Fund for Hardship
- T97.30 Half Year Income/Expenditure Report
- T97.31 Task groups
- T97.32 Strategic Plan
- T97.33 Hepatitis/Recombinant Campaigns
- T97.34 Any other business
- T97.35 Date and time of next meeting

### T97.25 Apologies

An apology was received from Dr David Evans. Philip Dolan had informed the meeting that he would be delayed due to his flight being cancelled.

The Chairman welcomed the new Trustees to the Board.

### T97.26 Minutes of the last meeting held on 30th May 1997

Following a brief discussion, it was proposed by Jan Hardy and seconded by Chris Hodgson that the minutes be accepted as a true record. Agreed unanimously.

### T97.27 Matters Arising

Details of the resumed AGM to approve the Annual Accounts, to be held at 2pm on Saturday 20th September 1997 at the Conference Centre, Strathclyde Business Centre, 199 Cathedral Street, Glasgow G4 0QU, were confirmed.

*Caring for people with haemophilia and other bleeding disorders*

Registered charity No. 288260. A company registered in England and limited by Guarantee. Registered Company No. 1763614.

**Trustee minutes 24 July 1997 (cont.)**

**T97.28 Election of Presidents**

The Chief Executive reported that there was a need to look at the current Vice-Presidents and their involvement in the Society.

It was proposed by Nick Lawson and seconded by Gordon Clarke that The Rev Preb Alan Tanner be invited to become a Vice-President. and that the Chief Executive produce a report on the circumstances of the existing Vice-Presidents. Agreed unanimously.

**T97.29 Tanner Fund for Hardship**

The Chairman reported that it had been proposed that the Society re-names its Financial Assistance Fund (Budget item 7606 on Expenditure Report) to the Tanner Fund for Hardship and accepts payment into that fund from other sources. Nick Lawson spoke in support of the proposal.

Mary Clark questioned the use of the word "hardship" and suggested that it may deter people from applying for assistance. Following further discussion Gordon Clarke proposed that the matter be referred to the Resources Committee for the agenda for their first meeting. The motion was seconded by Nick Lawson and agreed unanimously.

**T97.20 Half Year Income/Expenditure Report**

The Chairman reported that income and expenditure to date was in line with the budgets. However, John Pepper raised several questions with regard to specific items of expenditure and income on the report. The Chief Executive supplied answers to the questions and asked that should Trustees have questions regarding the Finance Reports in future, they contact him in good time before the meeting so that more detailed information can be supplied.

Gordon Clarke asked if the reports were to be issued on a monthly basis in future and the Chief Executive replied that they were. There then followed a discussion on bank charges and the Chief Executive reported that he had already approached the Co-operative Bank with a view to moving the Society's account and placing reserve funds elsewhere.

It was proposed by John Pepper and seconded by Bob Purnell that the Half Year Income/Expenditure Report be accepted. Agreed unanimously.

**T97.31 Task Groups**

The Chairman explained that the draft Task Group structure had been prepared during the Officer's meeting in Belfast earlier that month and invited comments.

### **Trustee meeting minutes 24 July 1977 (Cont.)**

John Pepper suggested that the Membership and Groups Task Group, which had been incorporated into the Resources Sub Committee be reconvened in its own right as it was an important Task Group. He also suggested that the Resources Committee should meet more often and that the groups should have a smaller number of participants. Various suggestions were made with regard to the make-up of the various Task Groups including moving Philip Dolan from the Parent Support Task Group to the Blood Products Task Group. Mention was also made of the problems in geographical locations and Trustee's difficulties in attending certain groups.

Graham Barker suggested awaiting acceptance of the Strategic Review before reconvening the Membership Task Group so that it would be clear who would be suitable for that group.

The Chairman suggested that it should be assumed that part of the Resources Committee will be involved in membership and that they would meet on the same day.

It was proposed by John Pepper and seconded by Jan Hardy that the draft Task Group structure for year to June 1998 be accepted. Agreed unanimously.

**T97.32**

#### **Strategic Plan**

The Chief Executive explained that the intention of the review was to ensure that the Society was "operating on a firm footing for the future" and Gordon Clarke commented that its aim was also to draw Trustees and staff closer together.

Written comments had been requested and the Chairman reported that he had not as yet received any comments.

Jan Hardy raised her objections to the final item of the Strategic Review which concerns Trustees and their role within the organisation. John Pepper agreed and endorsed Mrs Hardy's objections and added further comments.

Gordon Clarke explained that the Review was intended not only for Trustees and staff, but also for members, who would be unaware of what happens in the background with regard to Trustees, meetings etc.

The Chairman suggested that the matter should be dealt with at the Trustee's Weekend where more time could be devoted to it. Following further discussion Gordon Clarke asked that pages 1-6 of the Review (with regard to the 5 year strategy) be accepted.

## **Trustee meeting minutes 24 July 1997 (Cont.)**

Jan Hardy then asked if staff had access to a grievance procedure. The Chief Executive explained that they were able to turn to him and could take the matter further if necessary. It was pointed out that the Chairman visited the office once a week and it was agreed that staff should be made aware of this fact and that they could approach the Chairman with a grievance when necessary.

Nick Lawson reiterated the request for written comments on the Review to be sent to the Chairman and then proposed that pages 1-6 of the Strategic Review be accepted in broad principle. The motion was seconded by Jan Hardy and carried.

Graham Barker then asked at what stage the staff would have an input into the Review and the Chairman replied that their comments should be received before the Trustee's Weekend.

T97.33

### **Hepatitis/Recombinant Campaign**

The Chief Executive reported on the latest developments with regard to the Hepatitis C and Recombinant campaigns and mentioned the recently circulated list of Health Authorities and the four page Campaign Update that had been written by Graham Barker and the Chief Executive and designed by Sue Rocks.

#### ***Recombinant Campaign***

Graham Barker reported on various developments with regard to regional authorities who had now published reports on the matter of recombinants and had made decisions with regard to their supply to patients. He also explained that it was important to try to get Health Authorities to combine to buy recombinants in bulk, thereby reducing costs. The Chief Executive reported on the staff's involvement in the campaign and there followed further discussion.

#### ***Hepatitis C Campaign***

Gordon Clarke commented that there could be difficulties running two high profile campaigns at the same time. The Chairman explained that the forthcoming meeting with the Secretary of State for Health would also include a discussion on recombinants. He also explained that notes for the meeting were being prepared and Graham Barker was preparing briefing papers and notes to be sent to the Minister in advance. The Chief Executive explained how the campaign is being run.

Stan Cockburn asked the Chairman if a figure had been decided regarding compensation for Hepatitis C sufferers. The Chairman replied that some sums have been mentioned, but nothing positive has been settled. Jan Hardy said that there should be an equality with those who were infected with HIV.

John Pepper commented that the Chairman had not given a sufficient reply to Mr Cockburn's question. Gordon Clarke replied that at two meetings of the Hepatitis C

## **Trustee meeting minutes 24 July 1997 (Cont.)**

Task group it had been agreed that figures would not be attached and what would be looked for was an extension of the principle with regard to HIV sufferers.

[Mr Philip Dolan arrived at 5pm]

Following further discussion John Pepper suggested that the Chairman update Mr Dolan regarding the proceedings of the meeting after the meeting had closed. Mr Dolan agreed.

### **T97.34 Any other business**

#### **34.1. Letters to members**

Jan Hardy commented on a recent letter sent to members that had contained various errors. The Chief Executive assured the Board that it would not happen again.

#### **34.2 Trustees List**

Stan Cockburn commented on the list of Trustees and missing information. It was explained that once all the information had been collated, a new list would be issued.

#### **34.3 Strategic Review abbreviations**

Mary Clark asked that certain abbreviations contained within the Strategic Review be explained for the benefit of those who would later read the Review.

#### **34.3 Liaison between Trustees and Local Groups**

Gordon Clarke asked if any more thought had been given to the liaison between Trustees and Local Groups and it was agreed that the Chief Executive would draw up a draft list which would be circulated at a later date.

#### **34.4 Twinning with Russia**

Gordon Clarke also brought up the matter concerning the proposed twinning with Russia and informed the Board that a report has been drawn up which will be sent to Russia. The report outlines the six recommendations made at the Council Meeting on 26th April 1997.

Mr Clarke reported on the recommendations as follows:

1. Language learning: tapes are being acquired.
2. Information exchange: four information packs would be produced and sent at quarterly intervals.
3. Clinicians and Centre Directors: various Russian centres would be twinned with UK centres. Information on how the UK Society operates was particularly requested.
4. Information on concentrates etc would be supplied.
5. Pen pals: little response had been received so far from articles placed in The Bulletin, but further efforts would be made.

## **Trustee meeting minutes 24 July 1997 (Cont.)**

6. Exchange visits: it was suggested that over the next three years two children from Russia be invited to the UK to take part in adventure holidays. One person from the St Petersburg Society and one from the Moscow Society would also be invited to accompany the children to the UK and spend a week in the UK office and meet various groups. It was suggested that this would be more economical.

There had also been a recommendation that there be a World Federation workshop or conference in 1999, involving the Haemophilia Society. The cost of implementing the above recommendations was put at approximately £5,000 per year for three years.

It was proposed by Carolyn McGimpsey and seconded by Mary Clark that a more detailed report be prepared and in the meantime the principle of giving financial assistance to Russia be accepted. Agreed unanimously.

### **34.5 Trustee meetings**

Following discussion it was agreed that future Trustee meetings would start at 1pm and refreshments would be supplied as and when necessary.

### **34.6 Macfarlane Trust Weekend for Women and HIV**

The Chairman reported on comments contained within the draft report on the Weekend for Women affected by haemophilia and HIV held in Oxford in March 1997. Following discussion it was agreed in principle to approach people with HIV to work on the HIV Task Group. The Chairman asked Graham Barker as to the progress of the appointment of an HIV worker and Mr Barker replied that advertisements would be placed as soon as he returned from his holiday.

## **T97.35 Date and time of next meeting**

Following discussion, it was agreed that there would be a Trustees Weekend on 25th and 26th October 1997, the venue to be confirmed in due course.

The next Trustee meeting will be held on Thursday 25th September 1997 at 1pm.

There being no further business, the meeting closed at 5.45pm.

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