

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392233**

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Caring for people with bleeding disorders



THE  
HAEMOPHILIA  
SOCIETY  
UNITED KINGDOM

**Minutes of the  
EXTRAORDINARY TRUSTEE MEETING**

Held on Friday 19th January 2001  
At the Methodist International Centre  
Euston Street, London, NW1

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**AGENDA**

- T01.01 Apologies for absence
- T01.02 Minutes of the previous meeting held on 30th November 2000
- T01.03 Matters arising:
  - a. (item T00.61) Update on Haemophilia Society appointments to Macfarlane Trust Board (user and treasurer)
  - b. (item T00.62) Local groups bank mandate and rules
  - c. (item T00.64) Meeting with Lord Hunt 24th January 2001

- T01.04 Campaign review – report by Paul Richards Communications and Politics Direct
- T01.05 South Wales group
- T01.06 BPL report of vCJD donor
- T01.07 Board calendar and trustee attendance at forthcoming events (Local Groups Exam. 24th-25th February 2001)
- T01.08 Member letter: **GRO-D**
- T01.09 Any other business
- T01.10 Date of next meeting: Wednesday 28th February 2001

**Present:** Chris Hodgson (Chair); Philip Dolan (Vice Chair); Simon Taylor (Treasurer); **GRO-A** Nigel Hamilton [part of meeting]; George Levvy; Rona Macdonald; Carolyn McGimpsey; Alex Susman-Shaw.

**In Attendance:** Karin Pappenheim (Chief Executive); Sue Rocks (PA to Chief Executive) Paul Richards (Paul Richards Communications) John Arnold (Politics Direct) David Beamer (Politics Direct) Anne-Marie Piper (Paisners Solicitors)

**T01.01 Apologies for absence**

Apologies were received from Keith Colthorpe, who was unable to attend and Nigel Hamilton, who had been delayed.

**T01.02 Minutes of the previous meeting held on 30th November 2000**

The minutes were discussed and then agreed as a true and correct record.

**T01.03 Matters arising:**

**a. (item T00.61) Update on Haemophilia Society appointments to Macfarlane Trust Board (user and treasurer)**

The Chief Executive reported that two candidates had put themselves forwarded for the position and arrangements would be made for them to be interviewed before the next Board meeting on 28th February.

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NOT RELEVANT

**b. (item T00.62) Local groups bank mandate and rules**

The Chief Executive reported that the mandate and Rules had been amended and circulated to the local groups.

**c. (item T00.64) Meeting with Lord Hunt 24th January 2001**

The Society would be represented at the meeting by the Chief Executive, the Chairman and trustee GRO-A. There would also be representatives from the UK Haemophilia Doctors Organisation and the Haemophilia Nurses Association.

At this point, Ann Marie Piper was asked to clarify the Society's legal position with regard to the campaign. She reiterated the contents of her letter previously circulated to trustees and confirmed that any changes to be made to the aims of the campaign had to be approved by the Board of Trustees.

**T01.04 Campaign review – report by Paul Richards Communications and Politics Direct**

Paul Richards, John Arnold and David Beamer gave outcomes of their review of the campaign and took questions from the trustees. The review covered the media and political dimensions of the campaign and the consultants' report recommended changes in both strategy and aims.

It was agreed that if the recommendations made by Paul Richards et al were accepted, decisions regarding the implementation of the recommendations and costs would be considered at the next meeting in February.

Questions were raised about the timescale for the proposed campaign and the point at which if still unsuccessful the decision might be taken to end it. It was agreed that if the campaign were to go ahead as proposed there would be an ongoing evaluation and a further review in January 2002.

Trustees asked if Politics Direct considered that the Society had had a powerful enough voice in the campaign and Paul Richards replied that he could not find any mistake or issue that had not been covered but that a lack of clearly defined goals was a weakness.

There was further discussion on the media coverage of the campaign and whether recombinant should be a part of or separate to the HCV campaign. It was pointed out that the campaign aims had been changed to include recombinant at the special campaign review meeting held in September 2000.

Following further discussion it was proposed by Simon Taylor and seconded by Carolyn McGimpsey that:

**"The campaign objectives are exclusively:**

- a public inquiry into blood borne infections
- a hardship fund which would be a fixed total sum for the benefit of individuals affected by HCV on a case by case basis on evidence of hardship
- recombinant for all

**AGREED NEM CON**

It was agreed that before passing the aims, the Society should put the

**NOT RELEVANT**

It was agreed that, having agreed the aims, the Society should put the implementation of the campaign out to tender to other consultancies. The

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Chief Executive would co-ordinate this process before the Board meeting on 28th February at which an assessment of the costs of implementation of the proposals could be reviewed. It was further suggested that a panel consisting of the Chief Executive and two or three trustees review proposals from three or more competitive companies before the board meeting. Nigel Hamilton, Simon Taylor, Philip Dolan and [GRO-A] all offered to sit on the panel.

**T01.05 South Wales group**

Trustees were informed that following the withdrawal of the South Wales local group from the Society the members in Wales were to be asked their views on the formation of a new group. It was agreed that any monies remaining in the bank account of the group should be given to Haemophilia Wales (previously the South Wales group).

**T01.06 BPL report of vCJD donor**

The Chief Executive tabled copies of letters sent to Society members and haemophilia centres advising of the BPL report of a blood donor having been diagnosed with vCJD. She explained that the letter was sent after consultation with the UK Haemophilia Doctors Organisation and the Haemophilia Nurses Association who agreed that patients should be told. Individual centres would be taking their own action with regard to informing patients.

The Chief Executive also tabled copies of a letter sent to selected MPs and Lords in support of the Society's campaign, which accompanied a copy of the video of the Meridian TV programme "Blood Brothers".

**T01.07 Board calendar and trustee attendance at forthcoming events (Local Groups Forum 24th-25th February 2001)**

The revised calendar was noted. Carolyn McGimpsey, [GRO-A] Alex Susman-Shaw, Pat McAughey, and Phil Dolan said that they would be attending the Local Groups Forum in February.

**T01.08 Member letter [GRO-D]**

A letter received from ex-trustee [GRO-D] had been circulated and a draft reply from the chairman was tabled. Following discussion the contents of the letter were agreed.

**Member letter (Carol Grayson)**

A letter received from Carol Grayson which had been circulated in November was tabled together with a draft reply, which was agreed.

**T01.09 Any other business**

NOT RELEVANT

There was no further business to discuss.

**T01.10**      **Date of next meeting: Wednesday 28th February 2001**

The meeting closed at 4.40 pm.

GRO-C: Chris Hodgson

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NOT RELEVANT