

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392191



THE
HAEMOPHILIA
SOCIETY

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MINUTES OF THE BOARD OF TRUSTEES MEETING
Thursday 13 February 1997
Starting at 2.30 pm at the World Mission Association,
1st floor conference Room B, 157 Waterloo Rd, London SE1.

Present:

The Rev Prebendary Alan Tanner (Chairman), Mr Christopher Hodgson (Vice-Chairman), Mr Nicholas Lawson (Treasurer), Mr John Pepper, Mrs **GRO-A** Dr David Evans, Mrs Norma Guy, Mr Gordon Clarke, Mr Keith Colthorpe, Mr Andy Cowe.

In Attendance:

Mr Tony Wilson (Acting Chief Executive), Mr Graham Barker (Director of Services and Development), Mr Carlton Douglas (Membership Officer).

T97.01 Apologies

T97.02 Minutes of last meeting held on 22 November 1996

T97.03 Matters arising

T97.04 Future of the Bulletin

T97.05 Finance: 1997 Budgets and 1996 report

T97.06 Recombinant and Hep C campaign

T97.07 Any other business

T97.08 Date and time of next meeting

T97.01 Apologies

There were no apologies, Mr Andy Cowe was delayed. All members of the Trustee Board were present.

T97.02 Minutes of last Meeting Held on 22 November 1996

The minutes of the previous meeting held on the 22 November 1996 were accepted as a true record of the proceedings.

T97.03 Matters Arising

The Chairman informed Mr Tony Wilson that the Board of Trustees had unanimously decided to confirm him as Chief Executive. Mr Tony Wilson thanked the Board and added that he would do his utmost to serve the Society and its membership.

The trustees agreed to delay agenda item T97.04 until Mr Andy Cowe arrived.

T97.04 Future of Bulletin

A record of this item is placed at the end of the minutes.

RAISING FUND PEOPLE WITH HAEMOPHILIA

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T97.05 Finance: 1997 Budgets and 1996 Report

Mr Tony Wilson outlined the 1996 financial report and set the budget projection for 1997. The 1997 budget report was proposed for acceptance by Mr Nicholas Lawson, seconded by Mr John Pepper and accepted unanimously by the trustees.

After Mr Tony Wilson completed his report a discussion took place, of which a number of observations were made.

Mr John Pepper showed concern that there were no figures for 1997 expenditure. He reminded the trustees that no figures were produced for 1996 either. Mr Tony Wilson reassured the trustees that he will produce expenditure figures for the first two months of 1997 before the next trustees meeting.

Mr Gordon Clarke raised the question about the possibility of buying the lease covering the Fax and Photocopier machines. Mr Carlton Douglas is currently looking at the cost of purchasing new and second hand machines and will be reporting to Mr Tony Wilson on this matter. There is a twelve month period remaining on the lease of the photocopier. The lease for the Fax machine is shorter.

The trustees discussed the use of any surplus funds from 1996. The Chairman proposed that a part of the surplus be used for a grant to India for a piece of medical equipment. He also suggested a memorial to be laid in St Botolphs without Bishopgate for people who had died as a result of HIV infection, the thanksgiving service having been held at the church for a number of years. The Chairman would investigate costs and any further details.

Mr Nicholas Lawson explained that a part of the surplus funds from 1996, could be used for a new project in 1997 and that groups could be invited to make suggestions. He reiterated that legacy money can only be used for "pump priming" of projects or a one off venture.

Mr Tony Wilson will be meeting with local group chairs later in the year. The surplus funds for 1996 can be discussed and suggestions noted. Mr Gordon Clarke felt expectations of the groups could be raised, only to be disappointed when their suggestions were not met.

Mr Graham Barker reminded the trustees of other projects on the waiting list namely: Booklet on von Willebrands and weekend for 8-12yrs, as an alternative to the adventure holidays.

Mr John Pepper questioned the facts about the surplus and stated that care should be taken and reference should be made to the Society's overall cash position in relation to 1997. He felt income and expenditure should be as realistic as possible without drawing on reserves. He also observed that without the carried forward legacy surplus, the 1997 budget then becomes a deficit.

Mr Nicholas Lawson commended Mr Tony Wilson on the budget preparation, adding that it was acceptable to carry forward legacy income for use in the next year and for that reason, felt it was a balanced budget.

It was felt more discussion should take place after the audit for 1996, at the April Trustee Meeting.

T97.06 Recombinant and Hepatitis C campaign

Mr Graham Barker updated the trustees surrounding the present position on the Hepatitis C campaign and the availability of recombinant factor VIII. Current activities were contained in the report handed out to each trustee before the meeting.

Hepatitis C

The Society received a reply from Mr John Horam on behalf of the Prime Minister restating the Government's position not to provide financial recompense.

The two main actions proposed are:

- a) To secure a meeting with Mr Chris Smith (shadow Health Minister) and confirm the Labour Party's commitment to reassess the situation regarding financial recompense.
- b) To press for an Opposition Supply Day Debate on a motion calling for financial recompense.

Mr Alf Morris and Sir Geoffrey Johnson Smith will be retiring this term. The Society should try and find replacements who can be briefed.

There was some discussion surrounding the future of the campaign. Mrs. **GRO-A** voiced her disappointment over the present campaign activities. There was a general feeling of despondency among certain groups because of the lack of progress. A sense of urgency was felt lacking in some areas. Mr Graham Barker said that all of the mainstream lobbying techniques had now been used including the lobby of Parliament and petition to 10 Downing Street. The campaign group was looking to the Manor House Group for new ideas. It was accepted that greater communication needed to exist between the Society and the Manor House Group. The chairman suggested a meeting between the campaign group and Manor House Group.

Recombinant Factor VIII

The Society is involved in different ways, at different levels in different parts of the country. The campaign has developed into a more complex operation because there are more decision makers to target (health authorities, Trusts and consultants). It is important that the Society is actively involved by:

- a) Lobbying key organisations and individuals.
- b) Providing information to individuals thus empowering them to take action if they wish; and
- c) Clearly demonstrating its support to those parents and groups that are taking action.

The Department of Health is not endorsing the UKHCDO guidelines. Some centres in the South have provided their children with recombinant, also Oxford and the Scottish Office. Others in the North and the Midlands have been unable to get funding from the Health Authorities.

The Society is presently corresponding with the Health Authorities in the Manchester region and the Children's Hospital Trust to try to persuade the Authorities to continue to allow children to use recombinant. The Society is also liaising with the Manchester parents, local CHC and the solicitors representing the parents. The Manchester parents are also meeting with trust officials on 21 February, and would like representation and support from the Society. The Society intends to continue lobbying The Department of Health for support for guidelines and central funding for recombinant. Dr Chris Ludlam will be writing to The British Medical Journal outlining the disparity between regions.

Mr Graham Barker brought the trustees up to date with the VAT tribunal. The tribunal rejected the appeal by Baxter. VAT will therefore remain at 17.5% on Recombinant Factor VIII.

T97.04 Future of the Bulletin

Mr Andy Cowe gave a breakdown on a recent questionnaire distributed among staff, trustees and group chairman, about the present layout of the Bulletin. In his conclusion, he proposed the need for a major review of the Bulletin. It was agreed the style and presentation needed updating. The Chairman proposed the re-vamping of the Bulletin immediately.

Discussions arose regarding the possible influence on the Bulletin by pharmaceutical companies. The Chairman called for a vote on a proposal by Mrs Norma Guy, to decide whether the Bulletin was to be a future budgeted item. The final decision, was that the Bulletin would continue to be produced even if sponsorship was not forthcoming. However, companies who help fund the Bulletin via the "Pharmaceutical Industry Fund" will be thanked in each issue. This was seconded by Mr Gordon Clarke and unanimously accepted.

Mrs Norma Guy suggested an editorial board be formed to manage the Bulletin. Mr Tony Wilson expressed a desire to be part of this board. Dr David Evans believed the number should be kept to a minimum. The chairman agreed and recommended Mrs Norma Guy and Mr Tony Wilson in addition to Mr Andy Cowe and Dr David Evans to form a small editorial board.

T97.07 Any other business

Trustees were updated about the present situation regarding the Kent group. The Society's solicitors have advised Mr Tony Wilson against the suspension of the group. Mr Tony Wilson has written a letter of warning to the individuals involved.

Mr Nicholas Lawson and Mr Christopher Hodgson updated the trustees about a proposal for the Society's caravans. This involves a letting service. They will report further after a meeting in March.

T97.08 Date and time of next meeting

The next trustees meeting will be on the 16 April 1997. Time and location is to be decided.

Signed: _____

GRO-C

Mr Chris Hodgson

Date: 24th July 1997