

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

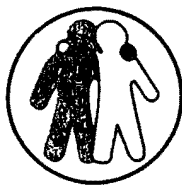
Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392062**

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**THE  
HAEMOPHILIA  
SOCIETY**

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**MINUTES OF THE  
EXECUTIVE COMMITTEE MEETING**  
held at Hotel Ibis, Euston on Saturday 7 May 1994

**Present:** Rev Prebendary Alan Tanner (Chairman), Mr Simon Taylor and Mr Chris Hodgson (Vice Chairmen), Mr Keith Colthorpe, Mrs Carol Holliday, Mr Julian Lander, Mr John Pepper,

**In Attendance:** Ms Susan Archer (Registrar), Mr Graham Barker (Director of Services and Development), Mr John Berry (Head of Fund-raising), Miss Jeni Mason (Resources Clerical Officer).

**AGENDA**

- E94.33** Apologies for Absence
- E94.34** Minutes of the last meeting held on Wednesday 13 April 1994
- E94.35** Matters Arising
- E94.36** Committee Reports:
  - 36.01** Services
  - 36.02** Resources
- E94.37** WFH - Mexico Congress
- E94.38** Policy on Financial Assistance to Members
- E94.39** Fund-Raising
- E94.40** Constitutional Review
- E94.41** Any other business
- E94.42** Date and time of next meeting

**E94.33** Apologies

Apologies were received from Mr Gordon Clarke, Dr David Evans, Mrs Norma Guy and Mr Nicholas Lawson

**E94.34** Minutes of the last meeting held on Wednesday 13 April 1994

The minutes were agreed with the following clarification to E94.27

Ms Archer will be writing to all Groups advising them of the changes and will invite the Groups to contact her with dates of their AGM's or other appropriate meetings for a visit from an Executive Committee member.

**E94.35** Matters Arising

There were no matters arising.

**CARING FOR PEOPLE WITH HAEMOPHILIA**

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**Publications:**

The Services Committee is considering proposals for changes to the Bulletin. There were no new developments on other publications. Dr Evans has agreed to do a publication on blood products.

**Prophylaxis:**

Mr Taylor reported that discussions on prophylaxis had been held with the Medical Advisory Panel. A series of articles will be written for the Bulletin to promote prophylaxis for children.

**Haemophilia Days:**

Mr Taylor reported that there is sponsorship for the next three Haemophilia Days which will take place after the summer.

**European Haemophilia Consortium:**

Mr Taylor reported that the EHC had met in Mexico and that the next meeting would be in Budapest in October 1994.

36.02

**Resources Committee**

In the absence of the Treasurer, Mr Nicholas Lawson, Susan Archer gave a brief report on the current issues of the Resources Committee.

**Office Premises:**

Ms Archer addressed two issues:

i) **The search for new office premises:**

Susan Archer, accompanied by Mr GRO-D, viewed five potential office premises last week. Ms Archer reported that they were not impressed, not all of the premises were appropriate and none could meet our full needs. However, the search continues but there may have to be a compromise on the criteria.

ii) **The situation of the lease of the old premises ,123 Westminster Bridge Road:**

Following the sale of the freehold the new owners have invoiced The Haemophilia Society for rent at the pro-rata rate of £20,000 per year. This has been referred to the Treasurer, for further negotiation. The Executive Committee agreed to leave this in the hands of the Treasurer.

**Income and Expenditure 1994:**

Ms Archer reported that although income and expenditure do not compare favourably with this time last year, there are various possible reasons for this. For example, the rescheduling of the annual mailing to companies and trusts, and the fact that more activities such as the AGM and a Haemophilia Day have already taken place this year.

Mr Pepper asked that in future the income report make comparisons with the budget and Ms Archer agreed that this could be done.

**Northampton Group Caravan:**

Following the agreement at the last meeting the Group have now purchased a caravan. The Committee noted this.

**Royal Victorian Ball:**

John Berry gave a brief update on the progress of the Victorian Ball. He thanked Chris Hodgson for his involvement in securing the first prize for the raffle, a Volvo.

**36.01 Services Committee**

The Services Committee met on Friday 6 May at Hotel Ibis. Mr Taylor gave a brief verbal report on the following issues:

**HIV Task Group:**

Following a meeting between representatives of the Birchgrove Group and members of the Executive Committee it was proposed that the Services Committee establish an HIV Task Group. The Services Committee agreed that Simon Taylor, Graham Barker, Norma Guy, [GRO-D], [GRO-D], [GRO-D] and [GRO-D] act as that Task Group. The Executive Committee was asked to note this decision.

Mr Taylor reported that the Birchgrove Group would like to hold a National Conference and the Society would support the Group in their proposed activities. Funding will be considered and pursued further. Graham Barker will be attending a meeting on Thursday 12 May in Cardiff to look further at this.

**Hepatitis:**

The pilot Hepatitis meeting and the article in the No: 1 issue of the Bulletin has generated a good response and members have contacted their local Centres for more information. A second Hepatitis meeting has been arranged for Saturday 21 May in Leeds. Dr Makris and Professor Preston from Sheffield have been invited to be the speakers. The format for this day has been changed to allow smaller group discussions to take place. Other Hepatitis meetings will be held before the summer. Possible venues are Edinburgh on 25 June and Bristol.

The issues of medical negligence and claims for compensation are being closely monitored. Work on hepatitis is overseen by the Task Group who will make sure that people have as much information on Hepatitis as possible.

**Blood Products:**

This is being kept under review. The Services Committee will inform of any developments.

**Children's Worker:**

A proposed work programme for the worker, which included consultation on a project, was discussed at the Services meeting. This paper will be redrafted and circulated to all members of the Executive Committee for comment.

**Chairman's Conference:**

Discussions have taken place with Alpha Pharmaceutical Company, who are interested in sponsoring a session on viral inactivation and safety. Porton would also be interested in sponsoring a session on inhibitors. The Services Committee will develop these ideas and others and they will be put to the Chairman for consideration in due course.

**Parents Support:**

As a result of a questionnaire on support to parents sent to all Groups and Centres many replies have been received and those who had not responded were being chased up. A report will be presented to the Council meeting in June. The Services Committee will keep the Executive Committee posted on issues as they develop.

A volunteer has been interviewed who seems suitable for starting work on the contact database.

Mrs Holliday mentioned that in the past Groups have contributed prizes for Tombola's at other Ball's. Mr Berry stated that there are plans for a Tombola in addition of the raffle and contributions from Groups may be appropriate. Mr Berry agreed to pursue this with the Ball organisers.

Mr Berry has regular contact with the Committee and receives minutes of meetings held, and agreed to keep the Executive Committee updated on any issues arising.

**Meeting Venues:**

Mr Taylor felt that the present meeting venue was unsatisfactory. Ms Archer reported that we were unable to secure our usual place at Charitybase and various other venues were also contacted but were either unable to cater for our needs or too expensive.

**E94.38      WFH - Mexico Congress**

The Congress was reported as an interesting event which had provided a great opportunity to meet doctors, health care professionals and for people to meet others in similar situations. Mr Cowe reported that the main issues covered were, Gene Therapy; Hepatitis C and Prophylaxis, Mr Barker has ordered various tapes and these will be made available to the Committee.

The Reverend Prebendary Alan Tanner, Chairman and Acting-President of WFH, had handed over the Presidency to Brian O'Mahony of the Irish Society who was elected to serve until 1996.

The next WFH Congress will be in two years and held in Dublin. The 1998 Congress will be held in Jerusalem.

**E94.38      Policy on Financial Assistance to Members**

Mr Barker circulated a paper on 'Grants to Members' at the meeting. Mr Barker introduced the paper and asked for guidance from the Executive Committee. The Chairman proposed that a task group be formed to look at the financial assistance policy. The Committee agreed that Mrs Carol Holliday, Mr John Pepper and Mr Keith Colthorpe form that group. The Committee members were asked to put their comments on the papers and give them to Mr Barker and Ms Archer.

**E94.39      Fund-Raising Presentation by John Berry**

A paper was circulated highlighting the major areas of fund raising activity over the last three months. Mr Berry began his presentation by thanking the Resources staff, especially Susan Archer, for all their support and advice.

Mr Berry then proceeded to present a fund raising strategy. He outlined some of the main areas on which the Society should focus and described a vision of a more "donor friendly" organisation.

The key elements in the strategy were Core Funding from Statutory sources, Trusts and Companies, Members and Individuals, computer database, Legacies and Fund Raising Events such as the Annual Draw.

**Statutory Funding:**

At present, the Society only received 5% of its funds from this source. Section 64 Funding for this year was only £32,000 out of a projected turnover of over £500,000. This was virtually the only guaranteed income the Society could rely upon. The aim was to increase statutory funding to at least 30% of core expenditure, to provide a more stable platform for the Society's

services. An application to the Scottish Home & Health Department was in progress for up to 30% of core funding, for three years beginning April 1996. The outcome of this application would be known by the end of the year. Other sources of statutory funding such as London Borough Grants were also being researched.

#### **Trust & Companies:**

Traditionally, the Society has received generous support from Trusts and Companies. Whilst there had been some notable successes, these had frequently not been built upon. Relationships need to be fostered through regular, personalised contact and feedback on progress. Improved targeting of institutions likely to be sympathetic to the Society was called for. The Society needed to seek funding for its work by dividing it into 'packages' which would be attractive to Trusts and Companies; a successful example of this was the sponsorship received from The Mercer's Company for the Hepatitis Days. Mr Berry had rung this trust to learn the outcome of the appeal.

In the past, the Society had undersold itself to funders by presenting a dowdy and unattractive image. The identical appearance and format of the Annual Review from one year to the next was a good instance of this. Photos of real people were needed along with stories of how the Society was making a significant difference to people's lives.

Mr Berry appealed to the Executive Committee to exploit any contacts they had for the benefit of the Society, citing Mr Hodgson's excellent efforts in obtaining a Volvo 440 at cost for the raffle planned for the Royal Victoria Ball.

The Chairman reported that he had received several enquiries from Livery Companies which had sent donations. The Chairman was not personally aware of these donations. Mr Berry will keep the Chairman informed in future.

#### **Members and Individuals:**

Last year, income from membership represented 14% of total earnings. The target was to increase this to at least 20%. One simple way of achieving this would be to send out up to three renewal reminders. Currently, only one reminder was sent out.

Better care was being taken of individuals who had chosen to support the Society with donations. In the past, gifts had often been treated as 'one-off's' and little attempt had been made to seek repeat donations. In future more emphasis would be placed on persuading individuals to make regular donations to the Society in the form of 'committed giving' such as covenants, Gift Aid and standing orders.

Work had already begun on making the Society more donor friendly. A target of five working days for acknowledging and thanking donations had been agreed. Every thank you letter sent out actively encouraged the donor to ring Mr Berry for further information. Personal contact had already been made with many people raising funds on our behalf. These were the first stages in establishing and strengthening relationships with our individual supporters.

#### **Database:**

Although not strictly speaking part of the fund raising strategy, the selection of a new computer database was crucial for its success. An integrated database, containing all information on members, donors and corporate funders was crucial to the work of the Society as a whole. From a fund raising perspective, it will allow better targeting and timing of appeals. More sophisticated segmentation of supporters into different categories would help us to focus appeals on specific areas of interest.

All staff had been given the chance to comment on a paper outlining the basic criteria on which a selection would be made. Staff would also be given a further opportunity to be involved in the process when a consultant had been engaged. Interviews for a consultant had already taken place and the search continues for the best possible solution with the available budget.

#### **Legacies:**

Legacies had made a vital contribution to the Society's finances in the past and would continue to do so for the foreseeable future. In recent years, we had been over-reliant on this source of income. Last year, 41% of income was derived from this source and £150,000 had been allocated in this year's budget. It would be extremely unwise to rely on receiving this amount.

In an attempt to secure more legacy income, a guide to Will-making was planned for publication in the Autumn. The guide would de-mystify the Will-making process and encourage people to make a bequest to the Society.

Initially, the guide would be promoted in the Bulletin and also by a direct mail shot to members and individual supporters, incorporating a letter explaining the guide, tear-off response coupon and free post envelope. A 'pledge card' would also be included to enable us to measure any response. For every pledge card returned, Smees & Ford estimate that there are four more in the pipeline. It was anticipated that there would be a very large number of requests for the guide.

#### **Fund Raising Events:**

There had recently been an upsurge in fund raising events on behalf of the Society. Lack of time prevented going into greater detail. Instead, Mr Berry concentrated on the Annual Draw.

Whilst not strictly an 'event', the Annual Draw had been a mainstay of the Society's fund raising for many years. Recent years had seen a sharp downturn in income; £22,000 in 1992 had declined to £15,500 in 1993.

In order to reverse this trend, a re-launch of the Draw was proposed for this year. The mailing to companies requesting prizes had already been sent and new prospects had been researched and approached. Rather than being buried along with a large number of other items, the tickets would be mailed as part of a special Christmas mailing at the end of August. Tickets would be priced at 50 pence each, in books of five, with ten pounds worth of tickets being enclosed with each letter. An income target would be set and members would be encouraged to sell a minimum of ten pounds worth of tickets. A prize would be awarded to the individual and Group selling the most number of tickets.

It was hoped that these measures would help to re-establish the Draw as a successful event as well as making it fun to take part in.

Mr Berry then summarised the main points of his presentation and invited any comments and questions.

**E94.40**

#### **Constitutional Review**

Mr Taylor proposed some ideas of possible changes to the Constitution. The areas focused on were the roles of the Executive Committee and the Council, he also highlighted the involvement of the wider membership.

The Executive Committee discussed Mr Taylor's ideas at length and agreed that he present these at the next Council meeting to open a discussion which will enable consultation and further exploration.

E94.41

**Any other Business**

**Venues:**

As a result of Mr Taylor's earlier comments on venues Ms Archer invited the Executive Committee for suggestions for a possible venue for the next Council meeting. It was agreed, subject to availability that the Council meeting on 11 June will take place at Hotel Ibis.

E94.42

**Date and time of the next meeting**

The next meeting of the Executive Committee will be Thursday 7 July 1994 at the changed time of 4.00pm. A Services Committee meeting will be held prior to the Executive meeting, proposed for 2.00pm. The venue will be at Central Office of Information, Hercules Road, London SE1.

GRO-C

Signed:

Chairman

Date:

7<sup>th</sup> July 1994.

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