

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392213



THE HAEMOPHILIA SOCIETY

The Haemophilia Society
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MINUTES OF THE EXECUTIVE COMMITTEE

Thursday 9 February 1995

held at COI, Hercules Road, London, SE1, Room G17, at 4.30pm

Present:

The Rev Prebendary Alan Tanner (Chairman), Mr Simon Taylor and Mr Chris Hodgson (Vice Chairmen), Mr Nicholas Lawson (Treasurer), Mr Gordon Clarke, Mr Keith Colthorpe, Dr David Evans, Mrs Norma Guy, Mr John Pepper.

In Attendance:

Mr Graham Barker (Director of Services and Development), Ms Susan Archer (Registrar), Mr John Berry (Head of Fund-Raising), Ms Jeni Mason (Resources Clerical Officer).

AGENDA

- E95.01 Apologies for Absence
- E95.02 Minutes of the last meeting held on Thursday 1 December 1994
- E95.03 Matters Arising
- E95.04 Hepatitis:
 - 04.01 Campaign
 - 04.02 Hepatitis Task Group
 - 04.03 Hepatitis Worker
- E95.05 1994 Audited Accounts
- E95.06 Services Committee Report
- E95.07 Resources Committee Report
- E95.08 Macfarlane Trust
- E95.09 Council Meeting, 1 April 1995
- E95.10 Any Other Business
- E95.11 Date, time and place of the next meeting

- E95.01 Apologies for absence

Apologies were received from Mr Andy Cowe and Mr Julian Lander. Mrs Carol Holliday was not in attendance.

- E95.02 Minutes of the last meeting held on Thursday 1 December 1994

The Minutes were agreed with the following statement from Mr Pepper to be added. These were proposed by Mr Taylor and seconded by Mr Clarke.

E94.83

"In the absence of any response from the Chairman to my letter of 9 December 1994 requesting amendments to minutes of items E94.82 and E94.83, I would like to withdraw this request in the interests of progress now that harmony within the Executive Committee has been restored."

- E95.03 Matters Arising

There were no matters arising.

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E95.04 Hepatitis:

04.01 Campaign

Mr Barker distributed a paper on Hepatitis C: Political Strategy, produced by GJW following recent discussions with a number of supporting MPs, for consideration by the Executive Committee. Mr Barker apologised for distributing this paper at the meeting and briefly outlined actions to be considered.

The Committee discussed the options of seeking recompense for all those infected with HCV at length and particularly for the 20% of those severely affected. The Committee agreed that the Society should proceed with the paper as it is drawn up by GJW and to campaign on behalf of all those infected. The Campaign Group will keep the Committee informed of further developments.

04.02 Task Group

The Task Group met on 25 January 1995. Mr Barker updated the Committee on its activities. The Hepatitis booklet has been produced in draft for comments from the Task Group. It is hoped that Schering Plough will produce 10,000 copies.

The Centre Directors Working Party has produced the Guidelines on the Diagnosis and Management of Chronic Liver Disease. These are now ready for circulation to Centre Directors. Mr Barker suggested that the Society publicise the guidelines in the Bulletin and approach Health Authority purchasers with a view to encourage them to ensure that the requirements in the guidelines are covered in their contracts or service agreements for haemophilia and that adequate funding is available.

Mr Barker reported that discussions have taken place with Bayer about holding a road show of meetings in a single week in May. The format and presentation are still in discussion.

04.03 Hepatitis Worker:

Mr Barker had circulated a paper on a project proposal for the Employment of a Hepatitis Worker. The Committee discussed the paper and approved the need for a Hepatitis worker. The post, on a six month contract, will be advertised in The Guardian within the next couple of weeks. The Hepatitis Task Group will keep the Committee informed at the next meeting of developments.

E95.05 Audited Accounts for 1994

Ms Archer apologised for not being able to circulate the accounts prior to the meeting as they were only received that morning. Ms Archer proposed that the Executive Committee hold an extra meeting on 1 April immediately prior to the Council Meeting to formally approve the accounts. In the meantime, the Resources Committee will discuss the accounts at their next meeting on 23 February.

E95.06 Services Committee Report

Item 1 on the Services report was discussed by Graham Barker at item E95.04.

Parents Support:

Mr Barker briefly reported that the information binder for parents of newly diagnosed children was being prepared by a writer employed by Bayer. He hoped it would be available within the next few months.

Applications for funding for a Children and Families worker have been submitted to Children in Need and the Roald Dahl Foundation. Discussions are being held with Positive Options for the team of volunteers child care workers to continue to provide crèche facilities at Society events.

Mr Berry reported that application forms for charitable organisations for the National Lottery will be available in June.

Publications:

- **Introduction to Haemophilia** is in the third proof stage. The time scale for production will be decided by Bayer.
- **Blood Products** produced by Dr Evans is in revised draft and will be circulated to the Executive Committee in due course. Factual details are being checked with the Pharmaceutical company.
- **Children's Haemophilia** booklet has been reprinted and the Society has over 200 copies in stock.
- **The Haemophilia Centre Directory** will be updated when the Centre Directors Regional Committee agree to the classification of two more Comprehensive Care Centres when the audit is completed.

Haemophilia Days:

The Services Committee agreed to hold four haemophilia days this year. The venues and dates have yet to be decided.

Hepatitis Days:

There are plans to hold two Hepatitis Days on Saturdays. Venues and dates will be confirmed later.

European Activities:

The EHC Conference will be held in London on 13-15 October 1995. A draft programme has been prepared for discussion with the Danish Haemophilia Society. Funding will be sought from Pharmaceutical Companies.

The Services Committee had agreed to the Society twinning with the Russian Society. Mr Taylor will contact the Russian Society to discuss further.

E95.07

Resources Committee Report**Office Premises**

Ms Archer met with Jo Anand from Paisner & Co on Monday 6 February to discuss the lease for 123 Westminster Bridge Road. There are a few legal points that are currently being clarified with Transmarine's Lawyers. Concerns were expressed about the proposed arrangements for building work. The Society would need to be clear on what work they are responsible for and what kind of compensation available when work is in place. Ms Archer assured the Committee that these concerns had been raised with our solicitor.

Ms Archer reported that the amount of £56,456 owing to British Rail had been written off in the 1994 Audited Accounts.

GRO-C Cover:

A report had been circulated outlining the arrangements for coping with Kate Richards', Member Services Officer, work whilst she is **GRO-C**. Shanit Marshall will deal with all member enquiries under the supervision of Graham Barker. A temporary secretary/clerical officer will be recruited on a short term contract to help with clerical work.

January 1995 Income and Expenditure:

Ms Archer apologised that as a result of the meeting being held early in the month she had not been able to complete the 1995 Income and Expenditure report.

Communications:

Mr Taylor has donated his mobile phone for office use but primarily to contact Mr Barker when working away from the office. The phone has not yet been connected as the Society is currently negotiating with Talkland for a reduction in the connection fee. The number will be circulated once connection has been made.

Chalet Purchase:

Contracts were exchanged on 27 February. The Chairman of the Birmingham Group will be responsible for the running and maintenance of the chalet. There are plans to launch a fund-raising campaign towards the purchase price. Ms Archer will continue to discuss the arrangements and fees for lettings with the Chairman of the Group.

Sheffield Group/Sheffield Children's Hospital:

The Sheffield Group has written to inform the Society that the Group no longer exists. The balance of £500 from their centralised banking account has been transferred to the Society. The demise of the Group will be formally reported to the membership at the Annual General Meeting.

The Resources Committee agreed to buy a television, video and a stand for use in the Haematology Unit at Sheffield Children's Hospital. The money reclaimed from the Group's account was donated to purchase those items. A plaque will be put onto the television stand to acknowledge the donation from the Society.

Forthcoming Fund-Raising Highlights:

Mr Berry briefly outlined a number of major projects coming to fruition. He reported that training for the Raiser's Edge software package had begun for four users and that the package would be up and running by 10 March.

E95.08**Macfarlane Trust**

The Chairman reported that the Trustees were considering an approach to the Government to replenish funds to support the Trust. The issue of widows was also discussed. The Chairman will report to the Committee on the developments as they occur.

The Committee confirmed the re-appointment of the Rev Preb Alan Tanner, Mr Clifford Grinsted and Mrs Norma Guy as Trustees of the Macfarlane Trust. The Committee agreed that it should consider nominating new people when the terms of office of existing Trustees come to an end.

E95.09**Council Meeting, 1 April 1995**

The Committee agreed that the main items for discussion at the Council meeting would be the Constitutional Review and Hepatitis.

E95.10**Any Other Business**

There was no other business.

E95.11**Date, time and place of the next meeting**

The Committee agreed to formally meet on 1 April immediately prior to the Council Meeting which will be held at St Thomas' Hospital in the Nevin Lecture Theatre.

The Committee will then meet on Tuesday 2 May. The venue will be confirmed at a later date.

Signed:

GRO-C

The Reverend Prebendary Alan J Tanner

Date: 1st April 1995.



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SOCIETY**

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123 Westminster Bridge Road
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MINUTES OF THE EXECUTIVE COMMITTEE

Saturday 1st April 1995

**held at St Thomas's Hospital, Nevin Lecture Theatre
at 10.00am (prior to the Council meeting at 11.00am)**

Present:

The Rev Prebendary Alan Tanner (Chairman), Mr Chris Hodgson (Vice Chairman), Mr Gordon Clarke, Mr Andy Cowe, Mrs Norma Guy, Mr Julian Lander and Mr John Pepper.

In Attendance:

Mr Graham Barker (Director of Services and Development), Ms Susan Archer (Registrar), Ms Jeni Mason (Resources Clerical Officer).

AGENDA

- E95.12 Apologies for Absence
- E95.13 Minutes of the last meeting held on Thursday 9 February 1995
- E95.14 Matters Arising
- E95.15 1994 Audited Accounts
- E95.16 1995 Annual General Meeting
- E95.17 Any other business
- E95.18 Date, time and place of the next meeting

E95.12 Apologies for Absence

Apologies were received from Mr Keith Colthorpe, Dr David Evans, Mrs Carol Holliday, Mr Nicholas Lawson and Mr Simon Taylor.

E95.13 Minutes of the last meeting held on Thursday 9 February 1995

The Minutes were agreed as a true record. This was proposed by Mr Hodgson and seconded by Mrs Guy.

E95.14 Matters Arising

Mr Hodgson asked for clarification to minutes E95.07 under Office Premises. It was reported that the amount of £56,456 owing to British Rail had been written off in the 1994 Audited Accounts

Ms Archer reported that at the last Resources Committee meeting it was agreed that the accounts should be rewritten to show the amount owed as a rent reserve fund pending the completion of the new lease. This had been discussed with the auditors and the accounts rewritten. The revised version had been circulated to all members of the Executive Committee.

E95.15 1994 Audited Accounts

Mr Clarke reported that, in the absence of Mr Lawson, he had chaired the Resources Committee meeting held on Thursday 23 February. As noted above, the Committee proposed a change to the 1994 Audited Accounts to reflect the situation regarding the amount owed in rent to British Rail. The accounts had been revised and copies had been circulated in advance of the meeting. Mr Clarke confirmed the amendment and presented the audited accounts to the Executive Committee.

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