

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392129



**THE
HAEMOPHILIA
SOCIETY**

The Haemophilia Society
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MINUTES OF THE EXECUTIVE COMMITTEE
Friday & Saturday 13/14 October 1995, at starting at 12.30pm
held at Forte Posthouse Hotel, 215 Haverstock Hill, Hampstead NW3

Present:

The Rev Preb Alan Tanner (Chairman), Mr Chris Hodgson (Vice-Chairman), Mr Simon Taylor (Vice-Chairman), Mr Philip Dolan, Dr David Evans, Mrs Norma Guy, Mr Keith Colthorpe, Mr Gordon Clarke, Mr Andy Cowe, Mr John Pepper.

In Attendance:

Graham Barker (Director of Services and Development), Susan Archer (Registrar), Melissa Watson (Resources Clerical Officer), Mandy Cheetham (Hepatitis Research Worker), John Berry (Head of Fundraising).

AGENDA

- F95.59 Apologies for Absence
- F95.60 Minutes of the last meeting held on Wednesday 20 September 1995
- F95.61 Matters Arising
- F95.62 Hepatitis Campaign
- F95.63 Hepatitis Research - Presentation by Mandy Cheetham
- F95.64 Future of the Services Committee
- F95.66 Fundraising
- F95.67 1996 Budget and Plan
- F95.68 Groups
- F95.69 Constitutional Review
 - EGM Council Meeting
- F95.70 Any Other Business
- F95.71 Date, Time and place of next meeting

F95.59 Apologies for Absence

Apologies were received from Mr Caddy Khudabux.

F95.60 Minutes of the last meeting held on Wednesday 20 September 1995

The following amendments were proposed by Andy Cowe.

50.01.01 Access to Information and Service Provision

Final paragraph, first sentence, add "in the final report" to read

"Mr Cowe requested that in the final report there be a section on the methodology, sample size of groups etc."

CARING FOR PEOPLE WITH HAEMOPHILIA

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E95.51 Constitutional Review

The first paragraph should be re-written as follows:

"Mr Cowe reported on the latest stages of the constitutional review. A draft memorandum & Articles of Association had been circulated to the Executive Committee. The documents comply with Company Law and embody the spirit of the proposed changes. Any issues should be raised with Ms Archer as soon as possible. The revised documents ensured that local groups would be recognised as an integral part of the Society and would not require individual separate registration with the Charity Commission."

E95.49 Matters Arising

The second paragraph to start "Mr Cowe" rather than "The Chairman".

These amendments were accepted by the Executive and the minutes approved.

E95.61

Matters Arising

Blood Products Policy

Mr Barker reported on a meeting with the Medical Advisory Panel where the proposed new Blood Product's Policy was discussed. He also raised the issue of a decision made by the Inland Revenue to put VAT on recombinant products.

Pharmaceutical companies had successfully argued in the past that albumin used in recombinant products is a human product and therefore not liable for VAT charges. HM Customs & Excise have recently changed their classification of these blood products, the pharmaceutical companies are appealing against the decision. Mr Barker suggested that the Society support their appeal by lobbying and trying to attract the interest of the press. The main issue is that people may be denied a safer product because of its increased cost.

Mr Taylor suggested that the Society's position ought to be marshalled through research into current standard practices of VAT charges, EC practices, other Pharmaceutical companies etc.

Mr Barker reported on the MAP response to the Society's new blood products policy. They were happy with the paragraph referring to blood plasma and that it must be screened for all known contaminants, using the best available techniques. They also felt that prophylaxis treatment is very important and should be promoted, particularly for children. The Chairman requested that a separate paper be put forward discussing prophylaxis treatment. The Society's policy on recombinant and high purity products caused some contention amongst the MAP panel. They felt that the strong wording would frighten people unnecessarily, who were on intermediate purity products, particularly as in their opinion 8Y product is one of the best products available. Mr Taylor suggested re-wording the policy to 'the Society believes that Intermediate Purity products ought to be phased out.'. This was agreed by the Executive. The exact wording of the policy statement will be discussed between Dr Evans and Mr Taylor and reported back to the Executive Committee.

EHC

Mr Barker reported that the EHC had 90 delegates and has adequate funding.

Macfarlane Trust

Mr Barker had sent out a reminder to the Executive regarding the appointment of a new trustee of the Macfarlane Trust. He asked the Executive if they had any suggestions. Mr Taylor proposed Mr David Watters as trustee because of his work with people with haemophilia and HIV. Mr Barker put forward three other nominations: **GRO-D** (nominated by Chris Hodgson), **GRO-D** (nominated by Norma Guy) works with people with HIV (nominated by Chris Harrington). Mr Barker enquired of Mr

Taylor whether he had spoken to other members of the HIV Task Group with regard to appointing a trustee. Mr Taylor replied that there had been no other suggestions. The Chairman then asked the Executive to vote for one of the four nominees. GRO-D got 2 votes, GRO-D 1 vote, Jerry O'Gorman 0 votes, David Watters was accepted with 6 votes.

Office Premises

Ms Archer reported that there are ongoing negotiations between the Society's and landlords solicitors regarding the lease. It will not be solved until various problems with the changes to the building had been resolved. This includes access difficulties and the inadequate lighting provision in the new entrance hall. Matters had been complicated by a recent fire brigade inspection and a leaking roof. It was suggested that the Society had outgrown the premises and that they were no longer suitable. The Chairman proposed that the Society look for new premises, which was agreed. Mr Lawson requested that legal opinion be clarified regarding any rent payments owed under the previous lease. Ms Archer agreed to refer the matter to Paisner & Co.

E95.62

Hepatitis Campaign

Mr Barker reported on the latest stages of the hepatitis campaign. It is going to continue with the same argument, but shift its priorities to focus on people who have already died, their dependants and people whose health has deteriorated, with a view to establishing a hardship fund. There will also be a debate in the House of Commons on Wednesday 18 October 1995 on blood transfusions.

E95.63

Hepatitis Research - presentation by Mandy Cheetham

Ms Cheetham gave a presentation on research she had conducted into hepatitis and concluded with recommendations. The Chairman invited questions from the Executive.

Mrs Guy requested a list of haemophilia centres and their varying standards of care. Ms Cheetham replied that this would be difficult because of the different criteria that centres and medical professionals use in defining a standard of hepatitis care.

Mr Clarke enquired about representation of the centres; how many were Comprehensive Care Centres and the geographical spread of centres chosen in the research. Ms Cheetham replied that she had tried to cover a broad range of centres, and believes that the geographical 'gaps' ought to be filled in at a later date.

Dr Evans asked what people's priorities were in terms of information. The research determined that people would like a 'factsheet' detailing insurance options, diets etc., which can also be targeted at specific groups e.g. young people.

The Chairman enquired how centres and centre directors have responded to Mandy's research work. She replied that centres vary in their attitudes, some felt that the Society had created a problem where there wasn't one and some were very helpful and supportive of her work.

Ms Cheetham reported that 60% of the people she had spoken to had not been offered interferon, 30% had been offered. She pointed out that there are strong reasons not to take interferon, though some centres are reluctant to offer it because of the cost. She had not found any cases of sexual transmission of Hepatitis C.

E95.64

Future of the Services Committee

Mr Barker introduced a paper to the Executive Committee which proposed the abolishment of the Services Committee, and a new reporting structure for Task Groups and Executive Committee, based on discussion's at the last Committee meeting.

The Executive Committee would be responsible for setting up task groups who would in turn report back to the Executive Committee. When the yearly budget is set, the Executive will define the responsibilities of the Task Groups. Each group will be chaired by a member of the Executive, who would be appointed by the Chairman. The task group can appoint other individuals to comprise the group, and must produce their own minutes, agenda etc. which are circulated to the Executive.

There will be a formal reporting procedure to be co-ordinated by Ms Archer and Mr Barker. The reports would highlight items for decision-making, and those for general discussion which will be considered at each Executive meeting. The Executive Committee would meet the same number of times a year, though they would last longer. The task groups would meet when they felt it appropriate, though not on the same day as an Executive Committee meeting.

Mr Taylor felt that he could not support the paper, although he did agree that the Executive ought to be more involved. He felt that if the Services Committee was removed the Executive would have no increase in authority and they would effectively be rubber stamping decisions already made in the task groups. He agreed that the situation ought to be considered and stated that the existing reporting lines work well enough already. He suggested that a new task group be established to examine the issue further, including the costs. Mr Clarke highlighted the need to choose the right chair for each task group especially as the task groups responsibility will increase.

The Executive members expressed varying opinions. Mr Clarke suggested that proposals from Executive members be put forward to Mr Barker who will present them to the Chairman before the next Executive meeting. The proposals must reach Mr Barker by 31 October 1995. They will then be proposed at the next Executive meeting. This was agreed by the Committee.

E95.65

Fundraising

Mr Berry gave a presentation on the Society's fundraising strategy. The members of the Executive enquired about various methods of fundraising such as national activities, scratch cards etc. Mr Berry discussed the issues that arise, and development areas e.g. membership, increasing core funding and making the Society's income more stable.

Mr Taylor asked Mr Berry how the Executive could assist with fundraising. Mr Berry replied that contacts within companies and other funding organisations are very important. Mr Taylor offered to assist him in developing more contacts. Mr Berry welcomed any support from the Executive for fundraising.

E95.66

1996 Budget and Plan

Ms Archer reported on revised income projections for 1996. She explained that there is an upward trend in general donations because local fundraisers are donating money to the National Office rather than a local group (especially as the number of local groups is decreasing). Mr Berry commented on how he encourages local fundraisers through building relationships with them and supporting their events.

Ms Archer reported on the planned changes to membership fees. The subscription for the first membership in each household will be £10, and for each additional member the fee is £5. There will also be a targeted campaign to remind people about their renewal fees. Mr Dolan enquired what would happen if members do not want to pay the increased fee and leave the Society. Ms Archer replied that there is a trend that individuals pay more than £5 anyway so many are unlikely to be affected by the changes. There will also be a drive to increase deed of covenants. Mr Taylor suggested that the Society be more pro-active in increasing the number of member donors e.g. through haemophilia centres.

Mr Barker reported on the expenditure plans. They were decided upon through discussions with the task groups.

Hepatitis: All related activities based on obtaining the Section 64 project grant. The Society is very confident that it will be successful, particularly as the Health Minister, Tom Sackville has continually mentioned hepatitis funding in letters to members. Most proposed activities are built on what centres propose and hepatitis C research.

HIV: The Society is less confident about being awarded the Section 64 grant in this instance because it would be the sixth year. The Birchgrove group has suggested a HIV weekend. Mr Barker proposed that if no grant was forthcoming then the event would not take place. This was agreed.

Woman's Weekend: This will not go ahead this year, but there is provision in the 1996 budget for research into holding a conference in 1997.

Bereavement Weekend: Funding has been applied for from the Macfarlane Trust, if it refuses then the event will not take place.

HIV Worker: The Society should apply to only one source e.g. one similar to the Roald Dahl Foundation. If the Society does not get funding to cover two years then it will not go ahead.

Parent's Support: The Parent Support pack will hopefully continue if there is a demand for it, at no extra cost to the Society. The Children's Worker sponsorship has been agreed. The Parent Support Network will hopefully be launched by the end of the year, though advertising and training costs need to be provided by the Society. The video is being funded partly by the Persula Foundation with a £6,500 grant, Mr Barker proposed that the Society provide the remainder, this was agreed.

Publications: All publications funding has been agreed through sponsorship.

Haemophilia Days: The sponsorship of these has ended after three years..

Financial Assistance Grants: The amount for 1996 has been increased to £20,000 because the Society has received a number of applications from people with hepatitis or affected by hepatitis e.g. a widow. Mr Barker asked the Executive how far the Society should go to supporting people affected by hepatitis. This will be for further discussion at the next Executive meeting.

Chairman's Conference: The money allocated may be more than what is needed, but £5,000 sponsorship has been found already. It was also proposed by Mr Barker that the Society employ a conference organiser which was agreed.

Twinning: If no funding is found then it will not take place.

The Chairman enquired how decisions are made on which items of expenditure will be chosen, and also which sponsors would be used. Mr Taylor replied that certain sponsors are targeted according to the expenditure item, e.g. for the Children and Families Worker post, the Roald Dahl Foundation was approached. Mr Barker added that the whole funding issue is ongoing and dynamic, whereby not one individual makes a decision.

Adventure Holidays: Ms Archer reported on the current situation with Adventure Holidays organised by the North Wales group. About four years ago the group was receiving £10,000 a year as sponsorship of the holidays, when the sponsorship ended the Society offered to assist the group. The group agreed to join the Society's centralised banking system and submit a budget plan every year. A plan was submitted in the first year and since then the Society has been supporting wholly the cost of the holidays without having any financial knowledge or control over how the money is spent. Mr Taylor proposed that the adventure holidays should be self-supporting, this was agreed.

Fundraising: Mr Berry reported on fundraising expenditure. There will be limited advertising of legacies in solicitors magazines because he feels that it is not cost effective. There is more provision for the Annual Report so as to improve the quality.

Office Equipment: The increase is due to the software being upgraded, which also affects the amount spent on training.

Salaries: It was proposed that the Society extend the existing contract for the Hepatitis Research Worker until March 1996 when it was hoped funding would be available to extend the post further. This was agreed

Mr Lawson proposed that the budget, with the above amendments, be approved, this was seconded by Mr Hodgson.

E95.67

Groups

Mr Hodgson and Mrs Guy reported on a project they had undertaken to examine how the relationship between Executive members and local groups could be developed. Their aims are to expand activities and reach those members who are not involved in local groups, and may be registered with very small centres. Mrs Guy commented that self help groups such as the Birchgrove have had a destructive effect on local groups whereby people are directing their support towards special interest groups. This is because the specialist groups represent the prominent issues affecting the haemophilia community, namely HIV and hepatitis. Mr Cowe agreed with the proposals but highlighted that there was no real mention of the present situation or system. He felt that the relative success of different relationships had not been recognised and therefore decisions cannot be based upon the present report. Mr Hodgson admitted this but added that there is still room for development.

Mr Pepper requested that each Executive member involved with a local group submit a report with recommendations etc.

Mr Dolan commented that some individuals complain that the Society is not very pro-active, however when it does organise an event, nobody turns up. He suggested that the Society employ someone to research into members needs and how to provide for them.

Dr Evans gave a historical perspective and pointed out how over the years the Society has changed in terms of what it offers, so much so, that what local groups originally provided is now being offered by the National Office.

Mr Taylor expressed strong support for groups, proclaiming them to be an important way for people to get in touch with the Society.

E95.68

Constitutional Review

Mr Cowe reported on the latest stage of the Constitution in view of the issues raised at the last Executive meeting. With regards to Proxy votes the solicitors recommended that a general proxy be adopted rather than a specific one. On the issue of whether the Chairman has a casting vote or lots should be drawn when, in the election process the votes for two candidates were equal, the solicitor had no opinion. The Executive voted on it, the result was split, so the Chairman exercised the casting vote in favour of the Chairman having the casting vote in the case of a tie.

Mr Cowe reported on the Birchgrove and Manor House groups integration into the Society. The negotiations are making good progress, but had raised three issues. Firstly it was recommended that the Society adopt a policy in the guidelines where they aspire to having 60% of the Executive Committee being composed of people with haemophilia. This was accepted by the Executive. Secondly, the Birchgrove group felt that the Society ought to have an equal opportunities policy. The Executive were satisfied that they do. Finally the group were very concerned about confidentiality issues. The Society would seek clarification of the legal requirements of the Data Protection Act

The solicitors were concerned about 'mini Birchgroves' almost becoming charities in their own right. Mr Cowe presented two models of organisation structure proposed by the solicitors to solve this problem. The Executive preferred the second model which involved three consultative groups reporting to the Executive. The Birchgrove group also wanted its own steering committee because of its specialised nature. The Birchgrove and Manor House groups have taken away the proposals and will discuss them before submitting revised proposals for consideration by the solicitors.

Mr Pepper commented that he felt the rules regarding group structure were too rigid and would not allow for a diversity of groups. Ms Archer replied that the rules are simply a skeletal framework which is a legal requirement, and would not restrict group activities.

E95.69

Any Other Business

No other business

E95.70

Date, time and place of the next meeting

29 November 1995 at 3pm. at World Mission Association, 157 Waterloo Road London SE1

Signed

GRO-C

The Reverend Prebendary Alan J Tanner

Date: 29 November 1995

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