

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392240



THE HAEMOPHILIA SOCIETY

The Haemophilia Society
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MINUTES OF THE EXECUTIVE COMMITTEE Wednesday 20 September 1995, at 3.00pm held at World Mission Association (WMA) Partnership House, 157 Waterloo Road London, SE1

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.

In Attendance:

Graham Barker (Director of Services and Development), Susan Archer (Registrar), Melissa Watson (Resources Clerical Officer).

AGENDA

- E95.47 Apologies for Absence
- E95.48 Minutes of the last meeting held on Thursday 13 July 1995
- E95.49 Matters Arising
- E95.50 Committee Reports:
 - 50.01 Services Report
 - 50.01.01 Access to information and Service Provision: Collaborative Project between the Haemophilia Society and the Birchgrove Group.
 - 50.02 Resources Report
 - E95.51 Constitutional Review
 - E95.52 Future Role of the Services Committee
 - E95.53 Revised 1995 Budget and Plan
 - E95.54 Macfarlane Trust
 - 54.01 Trustee Nominations
 - 54.02 Proposal from Services Committee: Observers
- E95.55 Approaches to the Patron
- E95.56 Any Other Business
- E95.57 Date, time and place of the next meeting
- E95.47 Apologies for Absence

Apologies were received from Mr Nick Lawson, Mr John Pepper and Mr Caddy Khudabux
- E95.48 Minutes of the last meeting held on Thursday 13 July 1995

The Minutes were approved as an accurate record of the proceedings. This was proposed by Dr Evans and seconded by Mrs Guy.

CARING FOR PEOPLE WITH HAEMOPHILIA

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E95.49 Matters Arising

Mr Cowe enquired, with reference to 95.43, whether the old system of executive members and their relationship with members was still in place. Mr Chris Hodgson replied that it was, and that new ideas on how to develop that relationship will be discussed at the Executive Weekend.

The Chairman enquired whether there had been any response to the solicitor's letter sent according to the decision made in 95.45. Ms Archer replied there had been no response from the individual concerned.

Mr Barker explained that the Society had supported the proposed changes in the rules and constitution of the WFH. Members of the Executive had been consulted but it was not possible to discuss this at the Executive Committee because the closing date for comments was in August.

E95.50 Committee Reports

50.01 Services Report

Mr Taylor drew member's attention to the minutes of the last meeting of the Services Committee and highlighted a number of issues.

Mr Taylor stated that the Hepatitis C booklet had been completed and is now available. He also went on to say that the Hepatitis Roadshow was running successfully.

Mr Taylor reported that the Services Committee wanted more support given to the Birchgrove Woodlands Project whereby members are asked to sponsor a tree. There is also a plan to ask the Medical Advisory Panel to develop a standard of care for HIV, similar to that done for people with HCV.

Mr Taylor reported that there is a wish for World Aids Day to be brought to the attention of the membership. It was proposed that a card be sent to all members. A Government grant would be applied for to fund the card. However he made the point that if funding was not forthcoming the Society would not support the project.

Blood Products Policy: Mr Taylor reported on the Society revising its policy with two significant changes:

- 1) All people with haemophilia should have the opportunity to use recombinant products.
 - 2) It is no longer acceptable for people with haemophilia to use intermediate purity products.
- The aim is to create a strategy that shifts people from using intermediate purity products to high purity and then finally to recombinant products.

Mr Taylor mentioned that there would obviously be conflicts of interest between various suppliers of blood products when trying to implement this strategy. The new policy and strategy will be considered by the Medical Advisory Panel.

EHC: Mr Taylor reported that Armour Pharmaceutical Company gave £2,500 rather than the expected £10,000. However, he stated that other sources of funding should ensure that the Conference will break even.

WFH: Mr Taylor reported on the plan for Russian delegates to arrive a day early to discuss how the UK Society could twin with the Russian Society.

The Executive agreed that the Bulletin advertise the Dublin conference and invite people to apply to be part of the UK delegation.

50.01.01: Access to Information and Service Provision

GRO-D had produced an interim report on the project that had been discussed by the Services Committee. The Chairman enquired how much was being spent. Mr Taylor replied that the cost of £3,000 was being split between the Birchgrove Group and the Haemophilia Society.

Mr Cowe requested that there be a section on the methodology, sample size of groups etc. This was agreed by Mr Taylor.

50.02 Resources

Office Premises: Ms Archer reported on the progress of building work, all the major work had been completed. Due to areas of uncompleted work there are ongoing negotiations with the solicitors about the lease. The resources committee had suggested that the building be modified with a ramp, which would involve re negotiations with the landlord.

Ms Archer proposed that a new telephone system be installed because of technical problems with the existing system. In addition the new system would be cheaper than the present one. This was agreed by the Executive Committee.

E95.51

Constitutional Review

Mr Cowe reported on the latest stages of the constitutional review. The document complies with Company Law and embodies the spirit of proposed changes. Any issues should be raised with Ms Archer as soon as possible. He highlighted a problem concerning the virtual independence of local groups and the effects on the Society's legal position. Their organisation is to be considered by the Society to redress the balance, and determine their actual status.

Mr Colthorpe enquired about the position on proxy votes, Mr Cowe agreed that it was unclear and said he would clarify it with the solicitors. In addition Mr Colthorpe felt that the clause regarding the honorary chairman having the casting vote when two candidates tied in an election was unsatisfactory. Mr Cowe agreed to refer that section to the solicitor.

E95.52

Future Role of the Services Committee

The Chairman raised the question of whether there is a future role for the Services Committee. He made the following points: the majority of issues brought to the Executive Committee are from the Services Committee, most of the Executive Committee members also sit on the Services Committee, and the role and decision-making capability of the Executive has been greatly reduced. He suggested that the Services Committee was no longer necessary. Mr Taylor made several comments in defence of the present Committee structure: the Services Committee was established to rid the Executive of detailed work, Executive meetings would be much longer if there were no Services Committee, there is currently a clear management structure that works well and has close links with Society staff.

The Chairman asked the opinion of other Executive members.

Mr Cowe reported on a discussion he had had with the solicitors. They believed that a system of standing committees would be more appropriate for the Society. Mr Cowe felt that the Services Committee was yet another reporting mechanism; as such it was unnecessary. The Chairman asked Mr Barker to produce a paper on this subject for the next Executive, in consultation with Mr Taylor. The Chairman suggested that any new structure must make clear the reporting responsibilities of the staff.

E95.53

Revised 1995 Budget and Plan

Ms Archer reported on the revised budget for 1995 taking into consideration unexpected expenditure e.g. hepatitis worker and income. The current performance is a deficit of £35,000 for 1995. Expenditure will not increase but future income is difficult to determine exactly. Mr Taylor expressed concern about the level of income, he suggested that more could be raised through fundraising activities. Ms Archer commented on several factors that affected the Society's ability to raise more funds. The installation of Raisers Edge (a computerised database) has taken much longer than anticipated, thus using staff time and resulting in lost opportunities. An important element of fundraising is the use of 'projects' which donors can choose and donate to. Ms Archer commented that there is very little forward planning within the Society whereby projects are decided upon months in advance. Hence the projects cannot effectively be used as part of a fundraising campaign.

It was proposed that Mr **GRO-D** attend the Executive Weekend and Executive Committee meetings to inform the Committee of his fundraising strategy and allow discussion on future projects.

E95.54

Executive Committee Weekend

Ms Archer reported on possible agenda items for the Executive Weekend. These were agreed by the Committee.

It was agreed that Mr Lawson be consulted regarding the payment of Mrs Guy's costs for the Executive Weekend.

E95.55

Macfarlane Trust

55.01 Trustee Nominations

Mr Taylor reported on the issue of trustee nominations. He suggested that the Executive Committee ought to consider in the long term, replacements for trustees of the Macfarlane Trust. Mr **GRO-D** of the Macfarlane Trust had explained the criteria for trustees. Mr Taylor stressed the need for the Executive to identify candidates as soon as possible.

55.02 Proposal from Services Committee: Observers

The Chairman stated that recently there has been much criticism regarding the Macfarlane Trust and would like to prevent an increase in friction between the Trust and the Society. Mr Taylor reported on the last Services Committee and commented that an area of criticism is the style of the staff at the Macfarlane Trust, in that they appear to influence the Trustees rather than the other way round. Another area of frustration is that the trustees are not felt to be as

close to the nature of the problem as they could be. This prompted the Services Committee to propose the idea of two registrants being observers. Copies of minutes would also be made available. Mrs Guy commented that discussion of certain issues at trustee meetings would be inhibited by the presence of an observer who was a registrant. Mr Clarke asked what the purpose of observers was. Mr Taylor replied that certain parties have expressed to him the concern that the Macfarlane Trust is not 'in touch' with registrants needs. In response to this statement the Chairman commented that issues such as these had been the subject of the review conducted by the Macfarlane Trust and clarified in meetings and discussions with, for example, the Birchgrove Group. However Mr Barker commented that registrants feel they should be more involved with policy making etc. The Chairman stated that people cannot be involved in decisions where they may benefit.

Mr Taylor speaking on behalf of the Services Committee proposed that the Society formally request the Macfarlane Trust to allow two registrants to regularly attend Macfarlane Trust trustee meetings as observers. In addition the Macfarlane Trust be asked to make available to the Society copies of minutes of trustee meetings. The first part was not accepted, but the second part was approved.

E95.56 Approaches to the Patron

The Chairman reported that the Patron had been approached by the Kent group to attend one of their events, without the officers knowing about this event. He suggested that more co-ordination in the matter of invitations to the Royal Patron would be more appropriate

E95.57 Any Other Business

Mr Barker reported on an event in Cardiff, at which tribute would be paid to Prof Bloom who had died. He asked if any of the Executive would be able to attend, bearing in mind the event was to be held during the weekend of the Executive residential session

E95.58 Date and Time of Next Meeting

The next meeting will take place on 13 & 14 October 1995 at the Forte Posthouse Hotel, 215 Haverstock Hill, Hampstead, NW3.

Signed:

GRO-C

The Reverend Prebendary Alan J Tanner

Date: 29 November 1995

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