

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392227

EXECUTIVE COMMITTEE MINUTES
Meeting held at Charitybase
Friday 29 October to Sunday 31 October 1993

From Saturday 30 October

Present:

Rev Prebendary Alan Tanner (Chairman), Mr Andy Cowe, Mr Gordon Clarke, Mr Richard Dickason, Professor Leo Evans, Mr John Pepper and Mr Paul Thompson

In attendance:

Ms Susan Archer (Registrar) and Mr Graham Barker (Director of Services and Development)

E93.76 Apologies for Absence

The absences of Mrs N Guy, Mr J Lander, Mr N Lawson, and Mr S Taylor were noted. Mr K Milne was unable to attend.

E93.77 Minutes of the previous meeting

The minutes were agreed as a true record of the meeting.

E93.78 Matters Arising

78.01 Medic Alert

This item was deferred until the next meeting.

E93.79 Staff and Premises Review

The Executive Committee having met on Friday 29 October, approved and adopted the review, steps will now be taken to implement the plan.

E93.80 Committee A Report

80.1 Office Premises

The Executive Committee agreed with the recommendation that the Society move from its current office premises to the Charity House at Cobalt Square. The proposed move is subject to draft documentation and a site visit by members of the committee.

80.2 Fundraising

Ms Archer reported on progress. Mr Thompson agreed to contact Mr Taylor regarding further developments on the statement for support.

The Northern Ireland Group were congratulated on their successful AGM and it was emphasised how important it was that Executive members attend such events.

E93.81 Committee B Report

High Purity blood products

The Committee agreed that it was dangerous to promote a policy without evidence, the establishment of a policy should be suspended until the research project is complete.

Needs Assessment

This was an opportunity for full executive to look at the report and make comments on both existing services and the recommendations on new services. Mr Cowe said that this was a very useful piece of work with excellent evidence and identification of needs. However, it is difficult to proceed until new staff structure in place. Mr Dickason said that there was unanimous agreement in Committee B, providing that he necessary staffing was in place, without this there was little hope of achieving the recommendations. He went on to ask for agreement that this be adopted as a new direction and new way of working.

Mr Thompson raised questions about the response rate to the questionnaire and expressed his interest in why more people had not responded. It was suggested that this reflects the historical relationships with members and that in reality the response rate is high compared to that within local groups on similar initiatives. It was suggested that this may form the basis of a research project after the member services appointment has been made.

HIV Report

It was reported that the HIV project team had met and produced a shopping list which had then been narrowed down list of priorities including the production of information sheets and support for the Birchgrove Group. Mr Taylor was discussing the Birchgrove proposals with the Terrence Higgins Trust with a view to forming a steering group. It is possible that there may be a project for support but no commitment has been given for direct help. Part of the current project proposal was for the employment of a worker, it was agreed that the Executive Committee needed to consider the implications of this. It was agreed that there were three important issues arising from the proposals to support the Birchgrove Group:

- involvement of the Society in the steering group
- legal status of Birchgrove Group
- employment contracts and supervision of staff

and it was further agreed that the Committee were not in a position to decide on any at this meeting. It was recommended that, in the meantime, Mr Barker continue to keep closely in touch with the Birchgrove Group and monitor the situation.

Support for Parents

Mr Pepper confirmed his endorsement of the whole project as a marvellous idea but expressed reservations about certain elements. Mr Barker agreed that the proposal formed a full programme of activities and recognised that it cannot all be done at once. The Executive Committee endorsed the proposals and agreed that this could form part of the brief of the new Member Services Officer.

Hepatitis

It is planned to hold seven half-day meetings around the country allied to publication of a booklet. Although there are potential difficulties with the time-scale of implementation of this project it was

agreed that in the light of claims being presented for legal action, this should be a high priority and should proceed as planned.

GIG

The Committee agreed to give £500 to the Genetic Interest Group towards the employment of a Parliamentary Officer, subject to GIG raising sufficient funds from other sources.

Europe Self Sufficiency

Mr Barker reported the need to maintain a watching brief but stressed that active involvement could take a lower profile unless there are major policy changes.

EHC

It was agreed that Mr Barker and Mr Dickason would attend the EHC meeting in Copenhagen and make the recommendation that the EHC adopt a constitution, governing body, and an agreed financial structure and reporting system. The Executive Committee also agreed that the continuance of the provision of the EHC secretariat will be dependent upon the new financial structure.

Health Circular

The Committee agreed that the implementation of the Health Circular may be adversely affected by the reduced role for Regional Health Authority's and that it is important to ensure that standards of care don't slip.

Haemophilia Days

It was agreed that Mr Dickason and Mr Barker would attend the Haemophilia Day in Stockport.

Armourpage

It was reported that there are problems envisaged with the proposed changes to the service. As a result, it was suggested that Mr Thompson and Mr Barker work on a response for those who haven't responded to the initial questionnaire.

Publications

There was agreement that the Hepatitis booklet is very important and should be printed regardless of sponsorship. It was agreed that Health Network be asked for a quote on the production of 2000 copies, on lower quality paper due to the shorter life-span of the publication, and that this amount be added to the Committee B budget.

E93.82 Budget

On the Internal Resources Budget, the following amendments were agreed:
The staff training budget should be increased to £4,500, in line with the recommendations in the staffing and premises review, the Executive Committee weekend should be included as a residential conference, the Information Management budget should allow provision for at least 3 months full-time employment at, £1000-£1300 per month, the Membership Development proposals should be added to the budget.

On the Services Budget, the following amendments were agreed:

The Hepatitis booklet will be published and included in the budget, the Chairman's conference should be included as a one-night residential meeting, the budget for grants should remain at the same level as for 1993,

In addition it was agreed that a copy of Health Network's contract and remit information should be made available for Mr Thompson who will then contact Health Network to discuss future issues and events. It was agreed that there should be a priority list for publications, and it was suggested, by Mr Cowe, that it would be better to go back to 4 issues of the Bulletin and cancel the publication of Update.

E93.83 Executive Committee member's visits to Groups

It was agreed that attendance at Group AGM's was important and it should be stressed that all invitations to such should be forwarded to relevant members of the Executive Committee. It was agreed that Mr Barker look at the proposed list of group visits and revise, if necessary before the next meeting.

E93.84 Council Meeting 20 November 1993

Taking into account the lack of time before this meeting, it was agreed that the agenda would mainly consist of an Executive Committee report and a panel presentation on comprehensive care. Professor Evans suggested that the panel include a Centre Director, nurse, pwh etc. and that questions be submitted in advance and also take questions from the floor. Each person would outline their understanding of haemophilia care. It was agreed that Mr Cowe would produce the executive report, Professor Evans would arrange panel presentation, in conjunction with Mr Barker who would co-ordinate the meeting organisation.

E93.85 World Federation of Haemophilia

The Chairman gave an update on current ideas and work of WFH. In order to organise attendance at the Mexico Congress the potential costs are needed, but it was agreed to follow the same principles as previous years. It was also agreed that Mr Clarke and Mr Cowe would represent the Executive Committee at the congress.

E93.86 Macfarlane Trust

the Chairman reported on recent events at the Macfarlane Trust including the slow start to the Eileen Trust, including the difficulties in identifying the recipients.

E93.87 Grants Committee

The Grants Committee met and discussed the following grant applications:

Dr C A Ludlam, Edinburgh, sought funding over two years for a project concerned with the use of gene therapy in the moderation of haemophilia A. The sum sought over the two year period is in the region of £30,000. The Grants Committee agreed to support this application in view of £12,000 raised locally and earmarked for a research purpose of Dr Ludlam. The Executive Committee agreed to make £15,000 available over the next year.

Dr J D Littlewood, Animal Health Trust, sought funding for research into feline haemophilia A as a preliminary to commencing activity in humans. The total sum sought for the project was in the region of £20,000. The Executive Committee felt unable to support the project at this time but asked that Dr Littlewood be invited to re-submit her proposal in the next financial year.

Dr G R Standen, Bristol, sought a grant of £7,000 for research into factor XIII deficiency. As the number of patients with XIII deficiency is very small, the Committee did not feel that this was a priority for the Society at this time, and the application was not approved.

Dr D I Gozzard, Rhyl, requested a grant of £1,850, plus VAT, for the purchase of a plasma thawing bath. The Committee agreed to support this application as money had been raised locally.

Dr T Baglin, Cambridge, sought a grant of just over £2,500 for an Elisa plate reader used in measuring clotting levels. This application was rejected on the grounds that we regard this item as standard NHS equipment.

Dr D R Prangnell, Lincoln, sought the release of further funds raised by the local group towards the purchase of a platelet aggregometer for Lincoln County Hospital. The local Group have raised a further £450 towards the total cost of the item. It was agreed that this amount now be made available to Dr Prangnell.

Mrs A F Sidebottom, Manchester is a Senior 1 Physiotherapist at Manchester Royal Infirmary seeking a grant of £650 plus VAT for the purchase of two eutrophic muscle stimulators for use with patients. The Committee agreed to support this application as money had been raised locally.

Dr A R Kruger, Truro, requested a grant of £1,080 as further funding towards the sessional cost of a physiotherapist for people with haemophilia in Truro. This application was approved in the light of the staffing problems at the Truro haemophilia centre and the inability to secure local funding through the hospital Trust.

E93.88 Any other business

Statement to be issued regarding staffing changes

It was agreed that a statement announcing staffing changes will be issued to all Local Groups, members of the medical advisory panel, centre directors and pharmaceutical companies. Health Network will be asked to co-ordinate the issue of such a statement.

Bank Signatories

Following the staffing changes, formal approval of a change to the authorised signatories on the Society's bank account was requested. It was proposed that Mr Watters name be removed from the list of authorised signatories and be replaced by Mr Barker. The signatories would now be as follows:

The Reverend Prebendary Alan Tanner, Mr Clarke, Mr Cowe, Mr Milne, Ms Archer and Mr Barker.

The Society's policy on signing cheques was that all cheques should have the signature of two authorised persons. These authorised persons are as listed above. Mr Barker could not be a signatory to a cheque of more than £2,500.

Mr Clarke proposed, seconded by Mr Cowe, that the above recommendation be approved, this was agreed unanimously.

Company Secretary

Following the staffing changes, formal approval of a change to the Company Secretary of the Society was requested. It was proposed by Mr Cowe, and seconded by Professor Evans that Ms Archer, now Registrar of the Society, become the Company Secretary. This was agreed unanimously.

Chairman of Committee B

In view of Mr Milne's illness, it was proposed that Mr Cowe take over as chairman of Committee B until further notice. Mr Clarke, as Treasurer, would take over the chairmanship of Committee A. This recommendation was proposed by xxx and seconded by yyy, and was agreed unanimously.

Richard

John

E93.89 Date of Next Meeting

The next meeting will take place at 3.30pm on Thursday 2 December 1993. It was agreed that all staff are to be invited for a pre-Christmas drink prior to the meeting.

SA

23 November 1993