

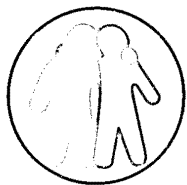
Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392214



THE
HAEMOPHILIA
SOCIETY

The Haemophilia Society
123 Westminster Bridge Road
London SE1 7HR

Telephone: 0171 928 2020
Facsimile: 0171 620 1416

MINUTES OF THE BOARD OF TRUSTEES WEEKEND MEETING

Friday & Saturday, 20 -21st September, 1996

starting at 2.00pm

held at the Holiday Inn, Brent Cross, Tilling Road London NW2

Present:

The Rev Preb Alan Tanner (Chairman), Dr David Evans, Mr Keith Colthorpe (*Friday only*), Mr Nick Lawson ((Treasurer), *Saturday only*), Mr John Pepper, Mrs Jan Hardy, Mrs Norma Guy, Mr Andy Cowe, Mr Gordon Clarke, Mr Chris Hodgson (Vice-Chairman)

In Attendance:

Mr Graham Barker (Director of Services and Development), Mr Tony Wilson, (Acting Registrar), Miss Melissa Watson (Resources Assistant), Dr Gozzard (*Friday only*), Dr Korn (*Friday only*).

AGENDA

Starting 2.00pm - Presentation by Dr Korn and Dr Gozzard of a business plan for the Continuation of the Adventure Holidays from 1997

Friday 20 September

- T96.71 Minutes of Last Meeting held on 11 July 1996
- T96.72 Matters Arising
- T96.73 Appointment of Chief Executive - report
- T96.74 Resources Committee Report (Tony Wilson)
- T96.75 Hepatitis Campaign Group progress report (Graham Barker)
- T96.76 Product Withdrawals and the Campaign for Recombinant Products (Graham Barker)

Saturday, 21 September

- T96.77 Report from the Constitutional Review Group
- T96.78 Report from each Task Group
 - a) Parent Support Task Group (John Pepper)
 - b) Blood Products Policy Task Group (David Evans)
 - c) Hepatitis Task Group (Andy Cowe)
 - d) International Task Group (Gordon Clarke)
 - e) Publications Task Group (Andy Cowe)
 - f) HIV Task Group (Norma Guy)
(including presentation by Cady Khudabux of a proposal for a worker)
 - g) Groups & Membership Task Group (Chris Hodgson)
- T96.79 Plans for Chairman's Conference and Council Meeting (Graham Barker)
- T96.80 Any Other Business
- T96.81 Date and Time of Next Meeting

CARING FOR PEOPLE WITH HAEMOPHILIA

N.B. The following items are ordered in the sequence that they were discussed at the meeting. They were taken out from the original agenda and placed elsewhere because there was time available to discuss them at that point.

Dr Korn and Dr Gozzard gave a presentation on the future of the Adventure Holidays, and their business plan for its future success. The Chairman thanked them for their time and assured them that there is guaranteed funding for the next two years. The Chairman also suggested that the responsibility for the holidays be passed to the Parent Support Task Group. Mr Clarke congratulated the North Wales Group volunteers for all their hard work.

The presentation highlighted the need to find future organisers once the existing volunteers resign from running the holidays. Moreover Dr Korn emphasised that there are a lot of publicity opportunities that the Society could benefit from if it were to take financial responsibility for the holidays. Dr Gozzard added there would still need to be a local link in North Wales, and that the Society would need to find another consultant following Dr Korn's departure.

Mr Pepper commented that there had been a lack of communication on both sides in terms of where the funding would be coming from and operational details about the holidays e.g. how many children attend and at what cost. Mr Clarke suggested a Holiday Committee be set up with a Trustee and member of staff. Mr Wilson reassured Dr Korn and Dr Gozzard that funding has been secured for the next two years, following donations from Anderson Consulting and Children in Need. The Chairman agreed to have a Committee, but added that North Wales group should also attempt to raise funds. Dr Evans asked why children from overseas were allowed to attend the holidays. Dr Korn replied that there is a reciprocal agreement with Italy, and has received many invitations from overseas organisations. It is also a valuable learning experience for all the children to be mixing with different cultures.

It was agreed by the Trustees to fund the Adventure Holidays for the next two years, and to reassess the different funding sources and volunteering in the Holiday Committee.

The Chairman thanked Dr Korn and Dr Gozzard for all their efforts and the presentation, they then left the meeting.

T96.71 Minutes of Last Meeting held on 11 July 1996

The following amendment to the last paragraph of T96.59 was proposed: to change 'with a viewing' to 'with a view'. The minutes were proposed by Mr Colthorpe and seconded by Dr Evans.

T96.72 Matters Arising

There were no matters arising.

T96.73 Appointment of Chief Executive - report

The staff left the room whilst the Working Party made a recommendation to the Board. On return, Mr Barker read out a letter from the Staff to the Trustees explaining why they did not

wish to accept the invitation to join the Trustees for an informal occasion. They explained that due to the uncertainty surrounding the appointment of a Chief Executive, they felt it would be more appropriate for them to meet, once the Trustees were able to speak about how it would impact the working operations of the National Office.

T96.74

Resources Committee Report (Tony Wilson)

Mr Wilson introduced the Resources Report, and explained that the existing budget was very difficult to manage and use, particularly as fundraising has been a priority. He added that the Society's finances are still under control. He described the huge difference between budgeted expenditure and actual, and the lack of clarity regarding the allocation of expenditure items.

Mr Pepper commented that the budget is not controlled and criticised the lack of forward planning when the Trustees had become aware of Susan Archer's [GRO-A]. He also highlighted the importance of correctly allocating income to expenditure. Mr Pepper asked why the actual sponsorship income was higher in April than in September. Mr Wilson replied that he had readjusted the figure to give a truer reflection on income. Mr Pepper commented that the layout of the budget is not very clear and is totally unsatisfactory. He suggested that there be differentiation between items dependent on sponsorship and those that are core activities.

Mr Hodgson enquired what the likely income and expenditure figure will be at year end. Mr Wilson replied that figures at the end of the third quarter pointed towards a break even at around £450k. The Groups income will also be brought in at the year end. Mr Clarke commented that as Trustees they did not have the level of information on the finances that is needed in order for them to provide financial direction. From the view of the Charity Commission there would appear to be very little financial control over the Charity. He then went on to suggest 'writing off' this year and using the remaining months to put the budgeting procedures in order for next year, and creating a system which directly links income to expenditure. This was agreed.

Mr Wilson reported on the office premises. Negotiations are still ongoing with no change from the last meeting.

Mr Clarke requested that in future local groups be informed of major staff changes at the National Office such as the appointment of a Chief Executive.

T96.75

Hepatitis Campaign Group progress report (Graham Barker)

Mr Barker reported on the Hepatitis Campaign. Following the end of the summer recess the campaign will become more active, although Manor House have successfully maintained a level of publicity over the summer. The Chairman enquired what the mood was of the Manor House Group, Mrs Hardy replied that they were optimistic.

Mrs Guy reported on a leaflet that has recently been distributed by the Blood Transfusion Service, it gives examples of when potential donors should not give blood. One of the guidelines was for a donor not to give blood for a year after having sexual intercourse with 'anyone with haemophilia or a related blood clotting disorder who has received clotting factor concentrates'. The Trustees discussed the appropriateness of the direct reference to haemophilia, it was agreed that the word 'haemophilia' should be removed. Mr Barker will make representations to the Blood Transfusion Service.

T96.76 Product Withdrawals and the Campaign for Recombinant Products (Graham Barker)

Mr Barker reported on the recent blood product withdrawals following the detection of hepatitis A virus. There has been much publicity surrounding this, which Mark Weaving at Health Network has manipulated into an argument for recombinant products which the press have picked up. Letters were sent to members informing them of which batches had been withdrawn, and to contact their centre if they were at all concerned. Mr Pepper reported that he had received a strong complaint from Dr Peter Jones in Newcastle because he wasn't informed prior to, or at least at the same time as the mailing. He therefore requested that he and other Centre Directors be informed of any future mailings.

Mr Barker reported that The Royal Free Hospital, partly as a result of media attention, has now committed itself to put all children on recombinant products within the next eight weeks. Dr Evans felt concerned that people may assume that hepatitis A is very serious because of all the media attention. However, Mr Barker argued that the point of all the media attention is that it proves existing viral inactivation processes are not 100% successful.

T96.78 Report from each Task Group

b) Blood Products Policy Task Group (David Evans)

Dr Evans introduced the report, much of which had been covered in the discussion on product recalls. Mr Barker reported that he was in correspondence with the National Blood Authority about the screening of donors in relation to CJD.

a) Parent Support Task Group (John Pepper)

Mr Pepper reported on the Parent Support Task Group, and said it was progressing well. The second edition of the 'Milestones' video is now being scrutinised. The Parent Support Network is quite slow to get off the ground in terms of number of users. However those who have used the network have said they received a very satisfactory service. Mr Pepper requested a report from Mr Barker on the progress of the Children & Families Worker, Peter Brown.

Mr Barker mentioned that some parents have requested a day event along the lines of Adventure Holidays. It was decided that this would be considered by the new Holiday Committee.

The Meeting ended at 18:00, to be resumed at 9:00 21 September.

T96.77 Report from the Constitutional Review Group

Mr Cowe introduced a review of the constitution and raised the issue of what to do with members who had not renewed. Mr Lawson had been speaking to Anne Marie Piper at Paisner's where he raised several issues. He suggested that there be a revision to the 12 member Trustee Board rule, the election of the Chairman and the six year rule of terms of office. Mr Lawson had sought clarification on the interpretation of Article 53(2), and asked whether a Trustee could stand in their fifth year as an officer which is for two years, thus increasing their term as a Trustee to seven years. He also asked whether serving Trustees could put themselves forward for election as both an Officer and as a Trustee. Mr Cowe then

distributed a letter to the Trustees from Anne Marie Piper at Paisners regarding proposed changes. She pointed out that any amendments to the constitution would have to be proposed at an EGM or AGM; and would incur costs which may not necessarily provide equal benefit to the Society. If amendments were recommended it would also create bad publicity not only in terms of the membership but also the Charity Commission who would question why the Society has had three different constitutions in the past three years. Mr Pepper agreed and felt that no more changes should be made. This was agreed by the Trustees

The Chairman thanked Mr Cowe for reconvening the Constitutional Task Group to consider these points.

Mr Cowe asked the Trustees opinion on members who had not renewed their membership, and whether they should continue to receive the Bulletin etc. The Chairman commented that it is politically important to be seen to be representing a large membership. Mr Clarke suggested putting non-renewing members in a 'suspended file' whereby they do not receive the Bulletin but are still members.

(T96.78 Report from each Task Group)

c) Hepatitis Task Group (Andy Cowe)

Mr Cowe reported on the hepatitis task group and referred to the minutes of the Task Group meeting held on 21st August. The Task Group had looked at ways of supporting local groups, it was decided that Bruce Norval act as the contact person. Mr Cowe reported that the Manor House Group had put in a Lottery application for a hepatitis field worker. The outcome is not yet known. The Chairman enquired whether the application was made through the Society. Mr Wilson replied that it was not. Mr Cowe then went on to highlight the importance of communication between the Society and the Manor House Group, particularly in instances such as the Lottery application, there is a need for funding applications to be integrated and not to overlap. The hepatitis worker, Deborah Gillespie, is producing hepatitis factsheets and is logging all calls and enquiries about hepatitis. Mr Barker is currently seeking funding for core activities and submitting S64 applications. He is planning to shift much of the funding for hepatitis project work into a core grant.

d) International Task Group (Gordon Clarke)

Mr Clarke reported that they had met informally in Dublin and had come to the conclusion that they were limited in the amount of support they could give to Russia. However, Russia did come up with some suggestions such as the Society providing books in English, a pen-pal database, provision of equipment, invited the UK Society to visit Russia. The Trustees agreed to these proposals apart from providing equipment which would be very expensive. A letter will be written to local groups asking them to contact their local education authorities for unwanted books. There will also be further opportunity for the Group to discuss their activities at the EHC meeting in Turkey in November, which both Mr Barker and Mr Clarke will be attending.

e) Publications Task Group (Andy Cowe)

Mr Cowe reported that Bayer have agreed to produce 10,000 copies of Haemophilia and School. The booklet on inhibitors is also being edited at the moment. Mr Cowe then made reference to Mr Peter Brown's request that the Society be connected to the World Wide

Internet. Mr Cowe felt that it would be inappropriate at this stage, and would like to ensure that real benefits would be gained, and also see a sustainable programme be created before going on the World Wide net. It was decided by the Trustees to leave the final decision to Mr Cowe.

Dr Evans asked Mr Barker to copy an article on the history of haemophilia, and handed out copies of an article he wrote about caring for children with haemophilia.

Mr Barker introduced the new Centre Directory, and highlighted some mistakes. He requested the Trustees to contact Tom if they come across any mistakes that have been missed.

g) Groups & Membership Task Group (Chris Hodgson)

Mr Hodgson reported that there have been three meetings of the above group. He read out part of a report produced by Mr Wilson on Groups and Membership. The Chairman invited comments. Dr Evans inquired about the Kent Group. The Chairman and Mr Hodgson outlined the latest developments. Mr Hodgson then informed the Trustees of his intention to go and visit the Kent Group, to discuss any problems they may have.

Mr Cowe raised the question of what action should be taken with dormant groups. This would be considered by the Groups and Membership Task group.

T96.79

Plans for Chairman's Conference and Council Meeting (Graham Barker)

Mr Barker reported that the registration form and programme has been mailed to members. He is still finalising speakers and workshops. He will also be contacting the Trustees nearer the time of the Conference on which Workshops they should chair. Mr Barker asked the Trustees to contact him if they wish to stay at the hotel on Friday night. Mr Barker invited suggestions for agenda items for the Council meeting.

T96.80

Any Other Business

Mr Cowe reported that the Scotland Centre Directors had recalled the SNBTS Factor IX products.

(T96.78 Report from each Task Group)

f) HIV Task Group (Norma Guy)

(including presentation by Cady Khudabux of a proposal for a worker)

Mrs Guy welcomed Mr Khudabux to the meeting who presented a proposal to the Board of Trustees on appointing a HIV Worker to provide support and advice to people with haemophilia and HIV, their partners and families. He read from a report that had been distributed to the Trustees. He argued that much of the support available to people with HIV is focused towards people who were infected through sexual transmission and drug abuse, not, for example a mother who injected her son with an infected blood product. There is also still much stigma surrounding HIV infection which in turn has led to people feeling isolated and unable to disclose their illness. Moreover these feelings of isolation have been exacerbated by cutbacks in haemophilia centres on HIV social workers. Research conducted by Birchgrove group has

identified people who have no knowledge on where to go for emotional support or advice on e.g. financial matters. He added that the Worker would be complementary to the needs of people with HCV. It is therefore proposed that a HIV worker be funded by the Haemophilia Society to address these issues, and identify solutions to help these people.

Mrs Guy expressed her strong support for this proposal adding that the people who are HIV+ cannot be relied upon for ever to try and offer the support to others, that is quite clearly needed. The Chairman added that the Society should provide more services for people who are HIV+. At the moment services are largely covered by the Macfarlane Trust, but the Society should begin to assume more responsibility for dealing with the non-financial aspects of support for people who are HIV+. Mr Cowe stated he was fully in support of the proposal but asked where the funding would come from. Mr Khudabux suggested the S64 grant that the Society receives for HIV work could be used. The Chairman commented that the expenditure of the S64 grant ought to be analysed more carefully to ensure expenditure is on HIV. Mr Pepper pointed to the 1996 expenditure and no money to date has been clearly spent on HIV work. Mr Barker stated that some money had gone to the Birchgrove Group each year. Mr Khudabux referred to the Millennium and the possibility of a 3-4 year plan for funding; he also felt that the worker should be a priority, Mrs Guy and Mr Pepper agreed. The Chairman then asked the HIV task group to formulate a job description to a view of appointing in 1997. The Trustees approved the appointment of a HIV worker and asked the HIV task group to formulate a job description and then work with the Chief Executive to produce a financial plan.

T96.81

Date and Time of Next Meeting

The next meeting will be held on 23 October in room G25 at the Central Office of Information, Hercules Road, SE1 beginning at 3.00pm

Signed:

GRO-C

The Reverend Prebendary Alan J Tanner

Date: 22 November 1996

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T96.82 Apologies.

There were no apologies as all members of the Executive Committee were present.

T96.83 Minutes of last meeting held on 20/21 September 1996.

The minutes were agreed to be a correct record of the meeting.

T96.84 Matters Arising.

David Evans expressed the opinion that it was inconvenient to change the day of meetings at the last minute. The Chairman assured David Evans that the point had been taken. Mr Keith Colthorpe explained that it would be helpful if Trustees could be informed of meetings by the end of November for the following year. Mr Tony Wilson explained that the next year's meeting dates were not ready at present, but they would be sent a list as soon as possible.

T96.85 Hepatitis C Campaign.

Graham Barker gave a report on the campaign. He informed the Trustees that he was in the process of planning a lobby at Parliament, which would take place in the beginning of December. He informed the committee that all council members and members would be given further details about the lobby.

He then gave a report on recombinant products and informed the Trustees that he had been in touch with the HCDO Board. He also informed the Trustees that Baxter had made an appeal against the amount of VAT that was being added onto recombinant and that they would be going before a tribunal in a few weeks time.

T96.86 Services Report.

A report was presented by Mr Graham Barker.

T96.87 Resources Report

d) 1997 Budgets.

Mr Tony Wilson presented a report on Resources, giving a financial summary of the organisation and outlining income & expenditure to date.

a) Office Premises

Mr Tony Wilson reported that negotiations surrounding the lease for the new office were still ongoing.

b) Staff Report & Changes

The Trustees agreed that Mr Tony Wilson would be retained in the capacity of Acting Chief Executive starting from 31 October 1996. It was decided that he would be monitored at 6 weekly intervals by a group consisting of Mr Chris Hodgson, Mr John Pepper and Mr Gordon Clarke and

who then would inform the Council members at the meeting on Sunday 24 November 1996. It was also agreed that the final decision regarding the position of Chief Executive Officer would be held off until the Trustee meeting scheduled for February 1997 in order to allow the appraisal of Mr Tony Wilson and to consider all other factors surrounding the appointment.

T96.88 Any Other Business.

Mr Graham Barker briefed the Trustees on the roles they were expected to play at the Chairman's Conference and indicated which workshops they would be chairing.

T96.89 Date and Time of Next Meeting.

It was agreed that the date would be decided at a later date.

Signed:

GRO-C

The Reverend Prebendary Alan J Tanner

Date: 13 February 1997