

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392223

To	Dave Tonkin		
Company			
From	Sue Roth		
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Tel No.		No. of Pages	(5)
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FAX
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**Minutes of the Trustee Meeting
(part 1)**

held on Friday 7 November 1997

at Forte Posthouse Birmingham City, Smallbrook, Queensway, Birmingham B5 4EW

Present:

Chris Hodgson (Chairman), Gordon Clarke (Vice-Chairman), David Evans (Vice-Chairman), Nick Lawson (Treasurer), Mary Clark, Stan Cockburn, Philip Dolan, Jan Hardy, Carolyn McGimpsey, John Pepper, Bob Purnell.

In attendance:

Julie Kershaw (Secretary/Administration Assistant)

Manor House Group: (Chairperson), (Secretary),
 (Vice-Chairman), (Member).

AGENDA

Friday 7 November 1997

- T97.45 Chairman's opening comments**
 - T97.46 Apologies for absence**
 - T97.47 Meeting with the Manor House Group**
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T97.45 Chairman's opening comments

The Chairman opened the meeting and explained that the Manor House Group had requested the meeting with the Trustees. He then read out a letter which had been received from the Manor House Group and which raised several issues including the fact that the Group believed that a decision had been made to reconstitute the Campaign Task Group which would effectively mean the non-involvement of the Director of Services, Graham Barker except as a Consultant to this Group. The letter implied that by involving Mr Barker in the Task Group, the Society had broken an agreement.

Gordon Clarke asked whether Graham Barker had been asked not to talk to MPs and it was explained that when the group was reconstituted it had been decided that Graham Barker would not be involved in the group that visited Frank Dobson, the Secretary of State.

The Chairman also read out a letter which had been received from Anne-Marie Piper of Paisners Solicitors, which stated the legal position of a local group within the framework of the Society as defined by the Charities Commission.

Questions were then asked regarding the Labour Party Breakfast meeting which was attended by Graham Barker. The Chairman stated that Graham Barker had spoken with the Baroness Jay and on returning to the office had correctly contacted Eric Preston to write a paper on the transmission of HCV which was sent to Baroness Jay to clarify the Society's views.

T97.46 Apologies for absence

There were no apologies for absence.

T97.47 Meeting with the Manor House Group

The Chairman invited the representatives of the Manor House Group into the meeting.

GRO-A thanked the Trustees on behalf of the Manor House Group for giving them the opportunity to put forward their point of view. He began by stating that the Manor House Group had no intention of working against the goodwill of the Haemophilia Society.

He then went on to give the Group's reason for requesting the meeting. The first being that the Manor House Group had made numerous requests that the Chief Executive take up the role of lobbyist for the Society and attend Parliament at least once a week to put forward the case to MPs in much the same way as the previous Chief Executive did when the HIV Campaign was taking place. He stated that the Manor House Group understood that this request had been agreed upon unanimously by the Campaign Task Group and yet to date it had not been acted upon.

He went on to express concern that the Chief Executive had taken his annual holiday during the week of the Labour Party Conference and that it had been recommended that a representative from the Society attend to put forward the argument for financial recompense for Hepatitis C. However, representatives had attended the Labour Party Conference to put forward the case for recombinant. He emphasised that this was part of the campaign and that he does not disregard the need for safer treatment.

Mr **GRO-A** then went on to express doubts about the validity of Health Network attending the conference and the fact that the Manor House Group was not notified who would be attending. He explained that he had made a verbal request to the Chief Executive with regard to attending the conference and had been told that he could not attend.

He stated that a meeting had taken place between the Society and Baroness Jay, the Labour Party's Health Spokesman, without informing the members of

the Society and that Graham Barker had attended that meeting. He went on to say that he had no confidence in Mr Barker and had not had confidence in

him for three years. He reiterated that it had been agreed to restructure the Campaign Task Group, without the participation of Mr Barker. He also stated that letters had been sent out without being cleared with the members of the Task Group.

Mr GRO-A continued that he had never seen any guidelines for the group and when asked to clarify that statement he said that he had never seen a draft document of what is actually set down to state who does what and who can what. He stated that he considered this to be unprofessional and asked that these guidelines be drawn up for each Task Group.

GRO-A was then invited to speak. He introduced himself and gave a brief history of his involvement with the Society. He stated that although he had heard rumours via a third party to the effect that GRO-A GRO-A and himself were not in a position to represent the Society's views, he had been asked on numerous occasions to represent the Society. He added that he needed to feel he was supported by the Society and was asked who had given him the information. He declined to mention any individual. Both Mr GRO-A and Mr GRO-A reiterated their commitment to the Society and on being asked about their relationship with Mark Weaving of Health Network, Mr GRO-A said that he could tell them lots of things and that he had tapes.

The Chairman said the Society had never obstructed the Manor House Group and GRO-A said that he had never been told what to say and therefore no-one could complain about what he did say. He was asked if the Manor House Group felt that they were being kept in the dark and GRO-A replied that he felt they were being over ridden.

GRO-A was then asked to give his views and he stated that he would like the Society to listen to those people affected by hepatitis C and admit it had made mistakes. He said that there was a lack of help and information and not emphasis on the fact that hepatitis C was equally as serious as HIV. He believed that the Society had failed to acknowledge the professionalism of the Manor House Group and had not fully pushed the medical profession for information on hepatitis C.

GRO-A asked that the Society re-examine its approach to hepatitis C and look into whether it felt that it placed enough relevance on those living in the north of England and Scotland.

GRO-A then explained why the Group had made an independent application for Section 64 funds. The group had discussed the matter of applying for a joint grant with the Society. However, the Chief Executive had stated in a telephone conversation with Stan Cockburn that a joint application was not possible.

Stan Cockburn stated that he had tape recorded the telephone conversation that he had had with the Chief Executive relating to the Section 64 grant, but had inadvertently wiped the tape. However, he read from a transcript of the tape and offered to supply copies of the transcript to the Trustees. The Trustees asked that they be supplied with copies.

The Group had then put forward an independent application for funds to set up an office and drop-in centre in Manchester.

John Pepper asked if the Manor House Group had a proposal on how the Manor House Group and the Haemophilia Society could work better together.

Gordon Clarke then asked for clarification on certain points that had been brought up, such as whether the Manor House Group had a mission statement that they worked to. GRO-A replied that the group worked to one principle, that of ensuring that the lives of people with hepatitis C were given the same value as those with HIV.

Gordon Clarke asked whether the Manor House Group had made a request for guidelines regarding the Campaign and GRO-A replied that he had spoken to GRO-D, Graham Barker, Alan Tanner and Mark Weaving on what objectives they needed to work to, but had received no reply.

Gordon Clarke also asked if Mr GRO-A had taken steps to verify the rumours concerning his involvement with the Society. Mr GRO-A replied that he had not, but whether the rumours were true or not, the issue was still there.

It was finally agreed that the Society would reply in writing to the Manor House Group, and meet with them again in the near future. Meanwhile, the group would produce a mission statement for the next meeting.

There being no further business the meeting closed for the day.

**Minutes of the Trustee Meeting
(parts 2 & 3)**

held on Saturday 8th and Sunday 9th November 1997
at Forte Posthouse Birmingham City

Present:

Chris Hodgson (Chairman), Gordon Clarke (Vice-Chairman), David Evans (Vice-Chairman), Nick Lawson (Treasurer), Mary Clark, Stan Cockburn, Philip Dolan Jan Hardy, Carolyn McGimpsey, John Pepper, Bob Purnell.

In attendance:

Tony Wilson (Chief Executive), Graham Barker (Director of Services), Sue Rocks (Membership Officer).

AGENDA

Saturday 8th November 1997

- T97.48 Minutes of meeting held on 25th September 1997**
- T97.49 Matters arising**
- T97.50 Rules for Groups and liaison with Trustees**
- T97.51 Resources**
 - 51.1 Fundraising Strategy**
 - 51.2 Budgets for 1998**
 - 51.3 Tanner Fund for Hardship**
- T97.52 Recombinant Campaign**
- T97.53 Hepatitis Campaign**

Sunday 9th November 1997

- T97.54 Strategic Plan**
 - T97.55 Any other business**
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SATURDAY 8th NOVEMBER 1997

The Chairman opened the meeting and welcomed the staff members. He also thanked GRO-D GRO-D for attending and taking the minutes of the first part of the meeting held the day before. He went on to congratulate Graham Barker on his new post and expressed the thanks and good wishes of the Trustees for his work for the Society over the past seven years.

T97.48 MINUTES OF THE MEETING HELD ON 25th SEPTEMBER 1997

The following amendments were made to the minutes:

- T97.37(T97.33) Hepatitis C Campaign**

It was pointed out that Stan Cockburn had proposed the motion and John Pepper had seconded.

T97.38.2 (T97.32) Strategic Plan

The minutes was amended to read: "Jan Hardy asked if the staff had been made aware that they could approach the Chairman with their problems if they had any and of the Chairman's presence in the office. "

T97.38.3 Blood Products Task Group Meeting

Para. 3 was amended to read: "Philip Dolan stated that in his view the Society was morally obliged to inform the membership. This view was supported by David Evans. However, David Evans stated that there was no evidence of CJD being transmitted through blood products."

Para. 6: The following was deleted: "..., therefore no further views should be sought."

T97.40 Financial Report to Date

The following paragraph was added: "The Finance Committee approved a sum of £5,000 to be spent on an emergency basis for the upgrading of the computers." *This was ratified by the Board of Trustees*

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T97.41 Consideration of the first draft of budgets for 1998

The following paragraph was added: "John Pepper drew attention to the fact that there was a £70,000 error to the addition side of the budget."

T97.42 Macfarlane Trust

The following was deleted: "...all should be asked to remain as Trustees on behalf of the Society and..."

John Pepper then proposed and Nick Lawson seconded, that the amended minutes be accepted. The motion was carried unanimously.

T97.49 MATTERS ARISING

(T97.38.3) Blood Products Task Group Meeting (Plasma products recall)

Following the motion that Graham Barker would write to Centre Directors to ask if they would be informing people of the recall, Philip Dolan asked for details of the replies received. Mr Barker reported that of the responses he had received, two Centres had decided not to tell people and three had informed their patients. He would be following up the others with telephone calls and had also spoken to Centre nurses.

David Evans reported that, having received the news of the first blood products recall, he had ascertained the details of the patient involved and had been informed that he was still healthy.

John Pepper asked if the letter from David Evans had been sent to members and Tony Wilson replied that it had not as the situation had changed, there having been two further recalls since. Mr Wilson gave an update on the situation and reported that he had had a telephone conversation with Dr Chris Ludlum and had been advised that the UKHCDO were to have an emergency meeting on 20th November to discuss the issue of CJD in detail.

Dr Ludlum had suggested that the Society await the outcome of that meeting before deciding its own policy. Graham Barker pointed out that the latest recall referred to the new variant CJD.

David Evans produced a statement he had prepared to be included in the next edition of the Bulletin.

CJD - are blood products safe?

The view from the Haemophilia Society by Dr David Evans

CJD is short for Creutzfeld-Jakob disease. It is a condition that affects the brain. The standard form of CJD has been known for many years. A new variant has recently appeared which is slightly different from the standard type, and is called nvCJD for short. This new variant is thought to be related to mad cow disease. Both diseases can take many years to show symptoms and as yet there is no test available for either.

There is no evidence that either disease is transmitted by blood products and as far as the Society is aware, there have been no cases of people with haemophilia contracting the disease from blood products anywhere in the world.

Nevertheless, as a precaution the National Blood Authority is recalling blood products that have come from people who have been found to develop new variant CJD. Other producers of blood products will also withdraw their products if a donor should develop CJD.

The National Blood Authority says that this is purely a precautionary measure and that there is no evidence that CJD can be transmitted between humans or through blood products. We agree.

The problem is that the donors concerned may have given blood many years before they developed CJD. If someone who has given blood later develops the disease it is very likely that any whole blood or blood products will already have been used; but it is common sense to recall any that may still be left over. There is no test for either type of CJD. The best that can be done is to screen donors to see if CJD runs in their family (some types of CJD run in a family).

The Society's policy is that if any risk to product safety can be avoided, then it must be avoided. That is why we are backing the NBA's policy of recalling blood products that have a connection to CJD, even though there is no evidence that they are a danger to the haemophilia community.

It is natural for people to be concerned about the safety of what they inject into themselves. Equally, it can be dangerous not to have treatment when it is needed. The advice that we offer is this: if you are in doubt or are worried about the products you are receiving, go and have a chat to your Centre Director. If you are still worried, you can call the Society's national office and we'll try to help.

Graham Barker added that the Department of Health were undertaking research into the risks of human to human transmission of nvCJD through blood and blood products. Tony Wilson added that there were other factors involved including the fact that SEAC (Spongiform Encephalopathy Committee) had recommended a precautionary policy of extending the use of

leucodepleted blood and blood products. He explained, for the benefit of the Trustees, what the process of leucodepletion involved.

John Pepper suggested that a rider be added to update members with information as it arises without alarming them. Graham Barker, however, said that this would be difficult as changes were taking place on a daily basis.

Following further discussion, Philip Dolan proposed and John Pepper seconded that Dr Evans' paper be supported. It was agreed unanimously that the paper should be published in The Bulletin.

There then followed a discussion on whether blood product batch numbers should be given out to members, if known. Dr Evans suggested that members should be referred to their Centre and it was agreed that batch numbers should not be given out by the Society.

(T97.40) "Jeans for Genes"

Nick Lawson reported that the Society had been turned down by the organisers of the above event. However, Mr Lawson said that he would continue his efforts to achieve Society involvement.

(T97.44.5) Leisure Great Britain Ltd

The Chairman reported that the privilege cards would be available as soon as possible. Nick Lawson asked if there should be a piece in The Bulletin advising members that only fully paid up or free membership members would be eligible for the cards. David Evans agreed to look into the matter.

T97.50 RULES FOR GROUPS AND LIAISON WITH TRUSTEES

50.1 Rules for Groups

The Chairman reported, for the benefit of the staff members, on the meeting with the Manor House Group that had taken place during the first part of the Trustee meeting the previous evening.

Stan Cockburn commented on the correspondence from Anne-Marie Piper of Paisners Solicitors which outlined the rules of the Charity Commission with regard to groups in relation to the Section 64 application made by the Manor House Group to the Department of Health.

Gordon Clarke pointed out that all Trustees present were representing the Society and the position should not be looked on as the Society versus the Manor House Group. He recommended a review of the rules for all groups and that new, revised guidelines be prepared for the future.

There was further discussion on the Manor House Group's Section 64 application. Graham Barker commented that the application put the Society's application at risk. Jan Hardy remarked that the Birchgrove Group received a Section 64 grant. However, Graham Barker replied that they did not, their funds came from the Welsh Office and the National Lottery. Following further

discussion Gordon Clarke stated that during the meeting the previous evening a suggestion had been put forward that the Hepatitis C Campaign be given to the Manor House Group. This prompted further discussion and then the Chairman suggested that Anne-Marie Piper's letter be adopted as a base for clarifying the role of Local Groups.

John Pepper put forward the following two part proposal:

1. Task groups to remain in force but numbers should be reduced to exclude all non-Trustees from the existing members. This will reduce costs, keep meaningless discussions to a minimum and ensure that the persons responsible for the legal and management responsibilities of the Society actually make the appropriate decisions. This may be varied from time to time by the Trustees to take advantage of the expertise available from others.
2. Whilst decision making power will ultimately rest with the Chairman of each Task Group, this should ideally be done with the agreement of the Chief Executive who should be consulted by the Chairman for any appropriate advice he may wish to offer before, during or after each meeting.

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~~Gordon~~ ^{GRAMAM} Barker said that the role of the Task Groups needed to be clarified and explained the original thinking behind the formation of the Task Groups.

Gordon Clarke read two proposals he had formulated during the meeting, both of which were seconded by David Evans. It was agreed that they be voted upon separately.

1. Agree that the Officers and Chief Executive develop a form of words which respond positively to the Manor House points. This would be submitted to Trustees before release to the Manor House Group.

AGREED UNANIMOUSLY

2. Agree that the Groups and Membership Task Group develop rules for groups, taking account of the needs of the Society and the Charity Commissioner's guidelines.

FOR 6 AGAINST 4 ABSTENTION 1 CARRIED

[At this point the meeting broke for lunch and reconvened at 2.15. Nick Lawson left the meeting and Jan Hardy was not able to attend the rest of the meeting due to illness.]

The Chairman asked for any comments on the letter drafted by Anne-Marie Piper.

Philip Dolan suggested that another Trustee should join the Membership and Groups Task group, namely Stan Cockburn. This prompted more discussion and the Chairman concluded that the Task Group should remain as it is.

Tony Wilson then suggested that the best way forward was that he produce a paper on the Task Groups. He then explained his reasons for writing a letter regarding the Task Groups to the Chairman. He pointed out that his understanding was that the Task Groups formulated strategy which was to be implemented by him.

David Evans commented that as the Chief Executive was probably bombarded with suggestions and views from the Task groups, a solution might be to cut down the number. It was finally agreed that Tony Wilson would report back with a paper on how he sees the Task Groups' role as part of the Society's management structure. Tony Wilson asked for the Trustees' opinions as to whether they thought the Task groups could be improved, and there was general agreement that they could. John Pepper then agreed to defer actioning his proposals until the report had been received. Philip Dolan then commented on the frequency of meetings and the necessity of knowing the dates in advance.

50.2 Departure of Director of Services

Tony Wilson informed the Trustees of measures to be taken as a result of Graham Barker, the Director of Services, leaving the Society. He stated that he already worked closely with Mr Barker and would take on the bulk of his work. He reported that he intended restructuring the staff to support him in this and would produce a separate paper for the Trustees' consideration.

Mr Wilson was asked if he would be employing other staff and he replied that he would not. Philip Dolan stated that the Trustees should be called upon to offer their expertise. Tony Wilson explained how the job descriptions of various posts had been changing and advised that he would send job descriptions of all staff once they were finalised to the Trustees, together with a staffing structure.

50.3 Trustees' liaison with Local Groups

The Chairman read out a memo from Graham Barker to Trustees outlining the details of the groups they were to liaise with. There followed discussion on what was expected of the Trustee, who would inform the Group of the Trustee's involvement and questions as to how the pairing of the two had been reached. Graham Barker explained how the decision were made, based on geography and in some cases, requests and stated that each group would be written to by the Society.

T97.51 RESOURCES

51.1 Fundraising Strategy

Tony Wilson spoke to the report prepared by GRO-D. The Board congratulated Miss GRO-D on the report and David Evans commented that Tony Wilson also deserves credit for his guidance and direction of fundraising.

Philip Dolan asked if Mr Wilson could clarify whether funds were raised from Trusts or corporate bodies as perhaps local groups were approaching their

own local corporate or Trust body. Mr Wilson explained that some Trusts or Companies would only give support at a local level and in such cases GRO-D would put them in touch with the appropriate group.

51.2 Budgets for 1998

Tony Wilson spoke to the report and replied to various questions.

Mary Clark asked if the situation with regard to the old office had been finalised and Tony Wilson explained that the Society had now received a Schedule of Dilapidation, but the final amount was still to be decided.

John Pepper asked various questions on expenditure and in particular with regard to the budget on events. He asked that the next Council meeting be held in Durham. There were comments about the high costs of Trustee and Task Group meetings.

51.3 Tanner Fund for Hardship

Tony Wilson reported and following discussion it was proposed by David Evans and seconded by John Pepper that:

"the Society's fund for financial assistance and the Tanner Fund for Hardship be combined to make one fund."

AGREED UNANIMOUSLY

It was also proposed by David Evans and seconded by Carolyn McGimpsey that:

"an extra £5,000 be added to the fund."

AGREED UNANIMOUSLY

Stan Cockburn asked if a date had been decided for the next Hepatitis C Women's Weekend and Graham Barker replied that a check was needed into the actual needs of that group of people, as decided at the last Task group meeting, and that GRO-D is looking into it.

T97.52 RECOMBINANT CAMPAIGN

Graham Barker reported on the latest position. He said that decisions had to be made and a White Paper should be issued before the end of the year. There was also a possibility of Centre Directors working with the purchasers of recombinant.

John Pepper reminded the Board that this subject was also dependent on the reply from the Minister of State for Health and asked if any news had been received. Graham Barker replied that he was in contact with the appropriate Civil Servants, but no reply had yet been received.

David Evans commented that with the recent nvCJD recalls recombinant has become a more important issue and should this not be pressed further.

Graham Barker explained the drawbacks to this move and after further discussion John Pepper proposed and Carolyn McGimpsey seconded the proposal that:

"a reminder be sent to Mr Frank Dobson, the wording to be left in the hands of the Chief Executive."

CARRIED

There was further discussion on the issues surrounding VAT on recombinant and the funding. Graham Barker stated that he was awaiting data from the Centre Directors.

T97.53 HEPATITIS CAMPAIGN

The Chairman stated that this area had already been covered and the Society was awaiting the reply from Mr Dobson. Following further discussion, Tony Wilson stated that the Trustees should look at the position after a reply has been received and what action should be taken depending on which of the three possible replies are received.

GRO-D stated that the Manor House Group had already formulated a plan for an aggressive campaign following a negative response. He was asked when the Society would be told of the plan and replied that **GRO-A** **GRO-A** would explain.

Tony Wilson said that a strategy needed to be ready, but in the meantime he had prepared three possible statements to be given to the press once a response is received.

Stan Cockburn stated that he wanted to make it clear that the Manor House Group will not do anything or make a statement without consulting the Society.

Tony Wilson read out one of the prepared statements and Stan Cockburn said he would speak to **GRO-A** regarding the Manor House Group actions in the future.

[At this point the meeting concluded for the day - 5.15pm]

SUNDAY 9th NOVEMBER 1997

GRO-C

~~The Chairman welcomed back Jan Hardy and then commented on remarks made by Stan Cockburn to Mary Clark during the previous day's meeting. Mr Cockburn apologised to Mrs Clark.~~

GRO-C

Tony Wilson then handed round a press release from the Department of Health concerning a CJD product recall.

T97.54 STRATEGIC PLAN

The Chairman handed over the Chair to Gordon Clarke who gave a presentation on the seven aspects of the strategy that had to be considered. He then split the Board into two groups for discussion.

Having discussed and made the necessary decisions regarding actions to be taken, the two groups combined and a member of each group explained the decisions made. It was agreed that a new version of the plan would be typed up, to include the actions and decisions made by the Board. This would be distributed in due course.

T97.55 ANY OTHER BUSINESS

55.1 Department of Health Press Release on recalls

Tony Wilson explained the details of the press release and said that more information was available from the office.

55.2 Presidents and Vice-Presidents

Philip Dolan raised the issue that had been discussed at two previous meetings and asked why the matter had not been included on the agenda. Tony Wilson replied that the item was dependent on a report from him, which he had been unable to provide due to other more pressing matters.

Following discussion, it was agreed that Trustees would contact Tony Wilson or the Chairman with any suggestions they may have and a report would be presented to the next meeting.

55.3 Fundraising Meal

GRO-C

Jan Hardy reported that a ~~friend~~ who runs a bistro was willing to provide a meal for £15.00, of which £5 would be donated to the Society. Tickets would need to be sold and the Board agreed to go ahead with the event.

relative of a member of the Parent Support Task Group.

55.4 Task Group Meeting Minutes

Carolyn McGimpsey asked if Trustees could be sent copies of the minutes from **all** meetings, not just their own groups'. It was agreed that all Trustee would be sent draft Task Group minutes after they had been approved by the Chairman of the particular Task Group.

There being no further business the meeting closed at 11.45am.

Signed:

GRO-C

Date: 27.11.97.

Chris Hodgson Chairman